Quality of Life of Colorectal Cancer Patients

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Declaration

This thesis has been composed by myself and the work contained herein is my own.

Signed

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Throughout my interviews with patients, I was very impressed by the amount of praise patients had for the staff involved their care.

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Abstract

Purpose: The aim of this study was to investigate the long term quality of life of colorectal cancer patients who had undergone either sphincter conserving or sphincter sacrificing surgery. It was predicted that patients who underwent sphincter-sacrificing surgery resulting in the formation of a stoma would report an inferior quality of life as indicated across several domains of quality of life compared to patients with no stoma.

Method: Thirty two patients completed a battery of questionnaires measuring quality of life at an interval of between twelve and eighteen months post surgery. Quality of life was measured using two questionnaires developed by the European Organisation for Research and Treatment of Cancer: one for cancer specific quality of life (EORTC QLQ-C30) and the supplementary colorectal cancer specific module (EORTC QLQ-CR38, Aaronson et al., 1988); Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983); Body Image Scale (BIS, Hopwood, Fletcher, Lee & Al Ghazal, 2001).

Data analysis: Patient age, length of time since surgery and scores on the measures were compared using independent samples t-tests. Length of time since surgery was analysed using covariance. Person's correlation co-efficient was used to test for the level of association between measures.

Results: No significant differences between the sphincter conserving and sphincter sacrificing groups were found on several domains of quality of life assessment including, physical, social, psychological and role functioning and levels of post-surgery symptoms. Significant differences were found between patients in relation to body image satisfaction and male sexual problems. Patients with a stoma showed more dissatisfaction with their body image than patients without a stoma. Males with a stoma were found to report more sexual problems than males without a stoma. Results are discussed in relation to previous

research and in terms of implications for further research and psychosocial aspects of care for colorectal cancer patients.

1. Introduction

1.1 Colorectal cancer

Incidence and prevalence

Colorectal cancer, also known as large bowel cancer, refers to cancer of the colon and rectum. It is reported to be the second most common cause of cancer in the United Kingdom, lung cancer being the most prevalent (Scottish Cancer Therapy Network, 2000). Despite improvements in early detection and treatment which have led to increased survival rates, colorectal cancer remains more common in Scotland than in many other developed countries and survival rates continue to be poorer than the European estimated average (Scottish Cancer Therapy Network, 2000). It is estimated that of 30,000 people diagnosed with colorectal cancer in the UK each year approximately 18,000 will die (Scottish Cancer Therapy Network, 2000). According to the Scottish Cancer Intelligence Unit Surveillance Group out of cancers diagnosed in Scotland in 1996 (excluding non melanoma skin cancer) 14% of 12,143 males and 13% of 12,809 females were diagnosed with colorectal cancer (Scottish Cancer Intelligence Unit, Annual Report 1997/98). During the last twenty five years, the five year survival rate for colorectal cancer in Scotland has increased from 25% to 45% (Scottish Cancer Therapy Network, 2000).

More men are affected by colorectal cancer than females with an estimated ratio of 1.3: 1 for colon cancer and 1.5:1 for rectum cancer although, different figures have been reported elsewhere (Fraser & Adelstein, 1982). It is suggested that women tend to be younger than men at diagnosis with mean ages of 55.1 years and 58.6 years respectively (Dukes, 1940). In addition women have been found to have a better prognosis than men, even after correction for their earlier age at diagnosis (Koch, McPherson & Egedahl, 1982). It is suggested that

this improved rate of survival among women is dependent on whether they have had children, nulliparous women having the same prognosis as men (Koch, McPherson & Egedahl, 1982).

Colorectal cancer is a disease that predominantly affects the older adult population (Engstrom, 1999). The incidence of colorectal cancer increases linearly with age between thirty and seventy years of age (Soybel, Bliss & Wells, 1987) with the largest majority of patients in their sixties (Bouchier, 1973).

Aetiology

Although dietary factors and certain diseases have been linked to the development of colorectal cancer (Bernhard & Hurny, 1998), it is estimated that approximately 75% of all new cases of colorectal cancer occur in people with no known predisposing factors (Winawer, Schottenfield, Flehinger, 1991).

In contrast, another study reports that dietary factors, such as a diet of high fat and low fibre content, are reported to cause between 80 to 90% of all cases of colorectal cancer (Engstrom, 1999). However, there are conflicting opinions regarding the involvement of diet (Stemmermann, Nomura, Mower et al., 1981; Thompson, 1982). Fielding & Padmanabhan (1994) suggest that these inconsistent interpretations are likely to reflect different methods of epidemiological study and statistical analysis.

A number of diseases are thought to increase the risk of individuals developing colorectal cancer including, familial polyposis, chronic ulcerative colitis and familial cancer syndrome (Bernhard & Hurny, 1998). Familial adenomatous polyposis is a

rare genetically transmitted disease in which benign tumours are found in the lining of the colon which leads to an increased chance of developing colorectal cancer (CancerBACUP, 2001). Ulcerative colitis is a condition in which the lining of the colon becomes inflamed. People who have this condition are more likely to develop colorectal cancer (Bernhard & Hurny, 1998). The term 'cancer family syndrome' refers to the exceptionally high incidence of cancer found in particular sites in some families, usually involving the colon, endometrium and breast (Argawal, Ulanhannan, Mandile et al., 1986; Fielding & Padmanabhan, 1994). In these families cancerous tumours tend to be found at an early age often involving primary cancer in several places (Fielding & Padmanabhan, 1994).

Symptoms

Commonly reported symptoms of colorectal cancer include pain, alteration in bowel habit, diarrhoea, constipation, blood in the stools, vomiting, weight loss and a feeling of bloatedness in the abdomen. The symptoms are variable and depend on the site of the lesion (Keddie & Hargreaves, 1968). It is estimated that physical symptoms are absent in approximately one third of patients (Bouchier, 1973).

Diagnosis

Early diagnosis is essential in maximising chance of survival (Bernhard & Hurny, 1998). A variety of different methods are used to diagnose colorectal cancer. The main diagnostic and screening methods are the faecal occult blood test, colonoscopy, sigmoidoscopy, digital examination and barium enema (Bernhard & Hurny, 1998). The faecal occult blood test is a test for hidden blood in the stool. A sigmoidoscopy is an examination of the rectum and

lower colon using a lighted instrument and a colonoscopy involves the same technique, the only difference being that the entire colon is examined. A digital rectal examination is a test in which the doctor inserts a lubricated, gloved finger in to the rectum to feel for any abnormalities. The barium enema technique involves the patient being given an enema that contains barium which then highlights the colon and rectum on x-rays. If any abnormal tissue is detected during these tests, a biopsy is then carried out to determine whether or not the person has cancer. This involves the specimen of tissue being examined under a microscope by a pathologist. Unfortunately, the early diagnosis of colorectal cancer is often delayed which may in part be due to patient delay in seeking medical advice through fear or ignorance (Fielding & Padmanabhan, 1994). It has also been suggested that diagnosis may be delayed due to the wide prevalence of gastrointestinal symptoms in the general population (Holliday & Hardcastle, 1979) and their increased prevalence in the older adult population (Curless, French, Williams & James, 1994).

Screening

In 1999 the National Screening Committee recommended that pilot studies be commissioned in England and Scotland to evaluate whether a national screening programme for colorectal cancer would be beneficial. A pilot screening programme is currently operating in Scotland hosted by Grampian, Tayside and Fife Health Boards. As part of this programme all men and women aged between 50 and 69 years of age within these areas are sent a self-administered faecal occult blood test. This involves a sample of faeces being taken which is then returned to the screening unit at King's Cross Hospital in Dundee where it is analysed for blood content. This is based on the knowledge that most cancers bleed producing blood in the stools (Simon, 1985). There have been four randomised, controlled studies evaluating faecal occult blood testing for colorectal cancer (Bevers & Levin, 1999). These trials

involved multiple, consecutive tests on an annual or biannual basis rather than a single test (Bevers & Levin, 1994). From the results of these trials it has been concluded that screening programmes are effective in reducing mortality rates although, there is some debate about the extent of this reduction (Bevers & Levin, 1985).

Staging classifications

The treatment offered to patients depends on the stage of the cancer which includes its size, position and whether it has spread (Cancerbacup, 2001). The different stages of cancer are described using the TNM (T= tumour, N= nodal involvement, M= metastasis) system which has replaced the Duke's system (see tables 1.1 and 1.2) (American Joint Committee on Cancer, 1997). It is compatible with the Dukes system but is said to add greater precision in the identification of prognostic subgroups. The TNM is based on the depth of tumour invasion into the wall of the intestine, extension to adjacent structures, the number of regional lymph nodes involved, and the presence or absence of distant metastasis. Staging is based on the natural history of the tumour which usually starts as a polyp with in situ carcinoma and then invades into the bowel wall. Metastasis refers to the cancer spreading to other areas of the body. In colorectal cancer this tends to occur via the lymph nodes or through the blood stream into other organs. Although cancer of the colon and rectum may spread to almost any organ, the liver and lungs are the most common sites (American Joint Committee on Cancer, 1997). Prognosis deteriorates as the stage of cancer advances (Engstrom, 1999). The TNM classification applies to both clinical and pathologic staging although most cancers of the colon or rectum are staged after pathologic examination of the resected specimen (American Joint Committee on Cancer, 1997).

Table 1.1: Definition of TNM classification. American Joint Committee on Cancer (AJCC), (1997).

	Primary Tumour (T)
TX	Primary tumour cannot be assessed
TO	No evidence of primary tumour
Tis	Carcinoma in situ: Intraepithelial or invasion of lamina proporia
T1	Tumour invades submucosa
T2	Tumour invades muscularis propria
T3	Tumour invades through muscularis propria into suberosa, or into nonperitonealised pericolic or perirectal tissues
T4	Tumour directly invades other organs or structures, and /or perforates visceral peritoneum
	Regional Lymph Nodes (N)
NX	Regional lymph nodes cannot be assessed
NO	No regional lymph node metastasis
N1	Metastasis in 1 to 3 regional lymph nodes
N2	Metastasis in 4 or more regional lymph nodes
	Distant Metastasis (M)
MX	Distant metastasis cannot be assessed
MO	No distant metastasis
M1	Distant metastasis
	Histologic Grade (G)
GX	Grade cannot be assessed
G1	Well differentiated
G2	Moderately differentiated
G3	Poorly differentiated
G4	Undifferentiated

Table 1.2: Colorectal cancer stage classification and grouping. American Joint Committee on Cancer (AJCC), (1997).

Pathologic description	AJCC (1997)	Astler-Coller Modification Duke's Stage
Carcinoma in situ	Stage 0:Tis, NO, MO	Stage 0
Tumor invades submucosa	Stage I:T1, NO, MO	Stage I-A
Tumor invades muscularis propria	Stage I:T2, NO, MO	Stage I-B1
Tumor invades muscularis propria into subserosa or nonperitonealized perirectal tissues	Stage II:T3, NO, MO	Stage II-B2
Tumor directly invades other organs or structures or perforates visceral peritoneum (or both)	Stage II:T4, NO, MO	Stage II-B3
Any degree of bowel wall invasion with regional node metastasis, without distant metastasis	Stage III: any T, N1-3, MO	Stage III-C1,C2
Any degree of bowel wall invasion with or without nodal metastasis but with any distant metastasis	Stage IV: any T, any N, M1	Stage IV-D

Prognosis

Prognosis is influenced by a number of factors at the time of diagnosis including age, general health, the type, size and position of the tumour, the extent to which the tumour has spread and whether it is possible to remove all of the tumour at the time of surgery (Chapuis, Dent, Fisher et al., 1985; Fielding, Arsenault & Chapuis, 1991).

Treatment

Surgery remains the most common form of treatment for colorectal cancer (Steele & Osteen, 1986; Zaheer, Pemberton, Farouk et al., 1998). It may be used alone or in combination with radiotherapy and chemotherapy (CancerBACUP, 2001). If the cancer is at an early stage surgery is often the only treatment required (CancerBACUP, 2001). A number of patients present as an emergency and undergo emergency surgery (Devlin, 1994). Most patients are prepared by specialist stoma-care nurses for the possibility that their surgery may result in a stoma. This preparation usually involves psycho-education as well as assessment of appropriate positioning of the stoma in the event that this is necessary (Devlin, 1994).

Type of surgery

There are several different types of surgery which are used in the treatment of colorectal cancer including, abdominoperineal resection, anterior resection, left hemicolectomy, right hemicolectomy and sigmoidectomy. During these surgical procedures the piece of the large bowel which contains the cancer is removed and the two open ends are then rejoined. The lymph nodes near to the bowel may also removed as this is the first place to which the cancer may spread (Cancerbacup, 2001). In cases where the bowel cannot be rejoined, usually if the tumour is situated too close to the anal verge, a surgical procedure known as a colostomy is performed. During a colostomy the open bowel is brought out onto the skin of the abdominal wall where an opening is formed known as a stoma. A bag is then worn over the opening to collect the stools. Often a colostomy is only temporary and usually a further operation to rejoin the bowel can be carried out a few months later although, it is suggested that the need for a second operation is likely to place additional burdens on the patient (O'Leary, Fide, Foy & Lucarotti, 2001). In the case of abdominoperineal resection a permanent colostomy is formed. Due to advances in surgical techniques there has been a

decrease in the number of individuals requiring a permanent colostomy (Heald, 1980). An ileostomy is a similar type of operation which involves the small bowel being brought to the surface with the formation of a stoma. The treatment of colorectal cancer is either by a curative or palliative operation (Bouchier, 1973).

Adjuvant therapy

Adjuvant therapy, such as chemotherapy and radiotherapy, is generally used with patients who may otherwise have a poor prognosis (Giles & Venables, 1994). It may be given either before or after surgery. It is more commonly given after surgery to eliminate any residual cancer and to reduce the risk of the cancer reoccurring. It may also be given when patients have developed secondary cancer in other parts of the body (CancerBACUP, 2001). The most effective sequence of surgery, radiotherapy and chemotherapy is not yet established and is the focus of on-going clinical trials (Engstrom, 1999). Reports on the effectiveness of both chemotherapy and radiotherapy are mixed depending on the disease stage and methods of treatment, and this requires further research before any firm conclusions can be made (Fielding & Padamanabhan, 1994).

1.2 Quality of life in colorectal cancer patients

Relevance of QOL to cancer

In recent years, quality of life evaluation has been recognised as an important outcome parameter in oncology along with traditional medical outcome indicators such as survival, disease recurrence, frequency and severity of symptoms (Buyse et al., 1984; Morrow et al., 1992; Poon et al., 1989; Sprangers et al., 1995). Many national oncology organisations and research grant bodies now recommend the inclusion of quality of life measures in clinical trials of new drugs and other treatment procedures (Clinical Trials Co-operative Group Program, 1988; Johnson & Temple, 1985; Jones et al., 1988; Luce et al., 1989; Moinpour et al., 1989; Osoba, 1992; Sadura et al., 1992). The need to take into account quality of life during survival has now become a central concern to many surgeons and cancer physicians and has contributed to changes in treatment approaches (Hopwood & McGuire, 1988). Most of the early research on quality of life in cancer patients focused specifically on breast cancer. However, in recent years this has extended to include other cancers (Bowling, 2001).

Definition of QOL

Although the term "quality of life" is frequently cited in the research literature, authors and researchers rarely provide its definition (Calman, 1987; Van Dam, F.S.A.M., Somers, R., & Van Beek-Couzijn, A.L.1981). Quality of life is a highly individual concept which is open to interpretation and is largely determined by individual preference (Calman, 1987; George & Bearon, 1980). So far, researchers have failed to agree on a consistent definition of quality of life. This has resulted in a diverse range of measures and methods being used to evaluate quality of life (Donovan et al., 1989; von Knippenberg & Dettaes, 1998) which at times has produced inconsistent results (Calman, 1987; Gruman et al., 2001).

It is generally agreed that any quality of life measurement used with cancer patients should be multi-dimensional in nature (Aaronson et al., 1988). It is also suggested that quality of life measurement should include both subjective as well as objective evaluations (George & Bearon, 1980). Clearly it would be inappropriate and overwhelming to incorporate all of the potential dimensions relevant to quality of life in one study. However, having reviewed the available literature relating to evaluation of quality of life in cancer patients there are identifiable themes which have emerged. Several researchers have focused on three main domains in their evaluation of quality of life in cancer patients which are: physical well-being (e.g. toxicity, nausea, pain, physical activity and recreation); psychological well-being (e.g. anxiety, depression, self-esteem body image); and social well-being (e.g. social support, social activities) (Maguire & Selby, 1989; Nayfield et al., 1992; Selby, 1993). Other areas which have been suggested as being relevant to perceived quality of life include the patient's reaction to illness (Miller et al., 1994), expectations of recovery and level of optimism (Higginson, 2000; Koller et al., 2000), spiritual, financial and cultural aspects (Calman, 1987). It is generally agreed that patients should be the primary source of information when assessing quality of life (Aaronson, Bakker & Stewart et al., 1987; Cella & Tulsky, 1990; McMillen, Moinpour, Hayden, Thompson et al., 1990; Siegnist & Junge, 1989). This recommendation is based on research evidence which has demonstrated wide discrepancies between patient self-assessment and doctors' ratings of quality of life (Padilla, Presant & Grant, 1981; Slevin, Plant & Lynch, 1988).

There are two schools of thought regarding whether a definition of quality of life should reflect the patient's pre-illness situation or the attainment of the quality of life aspired to (Calman, 1984; Schipper & Levitt, 1986). Ultimately this is likely to be determined by the individual values and judgement of the patient. It is suggested that the aim in medicine is

usually to return patients to their normal lives rather than to attain their ideal quality of life and that this should be reflected in the measurement scales used (Selby & Robertson, 1987). The measures should therefore include normal activities and areas of peoples' lives which are likely to have been affected by the specific illness, in this case cancer, and its treatment.

Two useful definitions of quality of life have been provided by Cella & Cherin (1998). The first is as follows: 'Quality of life refers to patients appraisal of and satisfaction with their current level of functioning as compared to what they perceive to be possible or ideal', Cella & Cherin (1998), p.1135. This definition was later modified as follows:

> Health-related quality of life refers to the extent to which one's usual or expected physical, emotional and social well-being are affected by a medical condition or its treatment.

Cella & Cherin (1998), p.1136.

These definitions highlight the difference between measuring quality of life in relation to an ideal situation and measuring quality of life in relation to a previously attained level of quality of life. For the purposes of this study which aims to measure the impact of surgical treatment for colorectal cancer on the lives of patients the second definition is more appropriate. The second definition also specifies the basic quality of life domains generally agreed upon in the research literature.

Impact of colorectal cancer on quality of life

Based on an extensive literature review, Ness et al (1998) identified areas of patients' lives which are reported to be affected by colorectal cancer. These included problems with social interaction, cognition, fear of cancer recurring, pain, fatigue, changes in bowel habits and sexual dysfunction. Focus groups involving people with different treatment outcomes were conducted to identify the degree of morbidity commonly reported among these groups. Although the specific areas of morbidity varied to some extent between groups, there was considerable overlap (Ness et al., 1998). It was concluded that morbidity in patients was related mainly to the type of treatment given (Ness et al., 1998), which is usually determined by the location and stage of the cancer at diagnosis (Cohen et al., 1997; Sprangers et al., 1995). The cancer itself was usually reported to be a minimal direct source of morbidity except in the case of metastatic or inoperable disease (Ness et al., 1998).

Impact of cancer diagnosis on quality of life

Although the survival rate for many forms of cancer has improved considerably in recent years, being given a diagnosis of cancer still evokes considerable distress in many patients (Fallowfield, Hall, McGuire & Baum, 1990). The word "cancer" carries powerful emotive connotations and for some patients is associated with impending death (McIntosh, 1974). There have been several reports of the endured psychological trauma causing patients to delay seeking help with potentially serious health implications (Hackett, Cassem & Raker, 1973; Watson, Greer, Blake & Shrapnell, 1984; Welsh, 1981). It is suggested that distress occurs with the first suspicion of cancer (Jamison, Wellisch & Pasnau, 1978), while the diagnostic period prior to surgery is identified as being the most emotional part of the treatment period (Northouse, 1989; Stanton & Snider, 1993). However, reactions to cancer diagnosis vary considerably between individuals (Derogatis, Marrow & Fetting, 1983;

Stanton & Snider, 1993). In addition to having to face the prospect of having a life threatening illness, patients also have to cope with uncertainty about the future and possibly unpleasant side-effects of the required treatment (Fallowfield, 1991). Psychological responses commonly shown by individuals following news of their diagnosis of cancer include shock and disbelief, feelings of anxiety, anger, sadness, and helplessness (Falek & Britton 1974; Greer & Silverfarb, 1982; Slevin, Nichols, Downeret et al., 1996). Patients may also experience feelings of isolation, guilt and a sense of stigmatisation (Dunkel-Schetter, Feinstein, Taylor & Falke, 1992; Frank-Stromberg, Wright, Segalla & Diekmann, 1984; Maguire, 1985; Miler, 1977). Fears concerning cancer recurrence, pain and death are commonly reported (Bloom, 1982). Fallowfield (1991) suggests that the impact of a diagnosis of cancer on well-being and quality of life may be influenced by other factors such as the perceived adequacy of information about treatment and prognosis. The extent to which these variables impact on quality of life is likely to be determined by a range of other factors such as the site of the cancer, stage of the disease and the likelihood of cure (Fallowfield, 1991). The emotional reaction to cancer diagnosis and adapting to the subsequent treatment stages may be conceptualised as a process of adjustment (Falek & Briton, 1974; Spencer, Carter & Price, 1998). Surgery often represents an important milestone for patients in terms of dealing with the emotional distress accompanying the news that they have cancer as often by this stage the prognosis is more certain (Spencer, Carter & Price, 1998). However, adjustment is a long-term process which is likely to continue beyond surgery and adjuvant therapy (Spencer, Carter & Price, 1998).

Impact of treatments on quality of life

Unfortunately, in some instances the psychological and physical consequences of treatment may impair quality of life to the same extent as the disease itself (Fallowfield, 1991).

Adjuvant therapies

Both chemotherapy and radiotherapy are sometimes used in the treatment of colorectal cancer. The possible side-effects of these treatments are well documented and may cause the patient considerable physical and psychological distress (Derogatis, 1986).

Radiotherapy

High-energy irradiation which is used to kill cancer cells can also damage healthy tissue in the process. This can lead to unpleasant side-effects such as skin inflammation, permanent alteration in skin pigmentation, skin atrophy and a reduced blood supply which can then reduce the skin's healing property if damaged in anyway (Fallowfield, 1991). Other commonly reported side-effects include nausea, vomiting and diarrhoea (Fallowfield, 1991). The physical side-effects associated with radiotherapy are to some extent determined by the dose administered, area of the body in which the cancer is located, and the care with which the treatment is delivered (Fallowfield, 1991). There are many side-effects which occur irrespective of the cancer site for example, unremitting and severe fatigue (Fallowfield, 1986, 1988). These particular symptoms may serve to reinforce a patient's belief that the cancer is treatment resistant. Fallowfield (1991) describes environmental factors which may play an important part in maintaining a patient's anxiety about radiotherapy treatment. For example, Fallowfield (1991) describes how warning signs in the clinic area and staff having to administer treatment from behind a lead shield may contribute to a patient's perception

that the treatment is dangerous and ironically may reinforce the belief that the method of cure is also a cause of cancer. Despite the numerous physical and psychological side-effects which inevitably impact on the patient's quality of life it is important to remember the potential benefits of such treatment. Radiotherapy can sometimes cure cancers which cannot be removed through surgery or in some instances is offered as an alternative to surgery. It can also be used as a palliative treatment as a means of reducing pain in advanced stage cancer (Fallowfield, 1991).

Chemotherapy

Fallowfield (1991) suggests that of all the treatments given to cancer patients, chemotherapy has the worst reputation. This is understandable given the range of side-effects associated with this treatment. Chemotherapy is used to kill cancer cells but at the same time may also damage healthy cells. Possible side-effects include hair loss, diarrhoea, vomiting and anaemia. Ettinger (1986) suggests that nausea and vomiting, which are side-effects likely to be produced by either chemotherapy or radiotherapy, are often the most distressing and disabling aspects of a cancer patient's illness. In cases where chemotherapy is given to cancer patients as an adjunct to surgical treatment, this may serve to reinforce the belief that the cancer has returned or remains untreated (Fallowfield, 1991). There is also the risk of damage to other organs due to high levels of toxicity (Fallowfield, 1991). Patients may still be adjusting to the effects of surgery when they begin their chemotherapy treatment. Fallowfield (1991) suggests that having to undergo a second form of treatment may serve to maintain patients' beliefs that the treatment has been ineffective and that the cancer has not been completely removed.

Hopwood & Maguire (1988) suggest that chemotherapy and radiotherapy are among other factors strong predictors of affective disorder in cancer patients. Maguire et al (1980) report from a study of breast cancer patients receiving adjuvant chemotherapy that the rate of depression doubled in this patient group. Several other studies have documented the contribution of radiotherapy to increased risk of developing an affective disorder (e.g. Lyon, 1977; Maguire, 1976; Peck & Boland, 1977).

Psychological response to impending surgery

Gruendemann (1965) refers to surgery as a 'planned physical assault' and suggests that most people feel anxious at the prospect of having an operation. Strain & Grossman (1975) describe several fears commonly expressed by patients awaiting surgery. These include threat to their sense of personal invulnerability, concern that one's life is being entrusted largely to strangers, separation from the familiar environment of home and family members, fear of loss of control or death while under anaesthesia, fear of being partially awake during surgery and of damage to body parts. Other worries expressed by cancer patients relate to post operative pain, degree of success of the operation, further treatment required and the possible side-effects involved as well as the financial consequences of a stay in hospital and period of recovery (Fallowfield, 1991). Gottesman & Lewis (1982) suggest that while these are normal reactions found to some extent in all surgical patients, these concerns are heightened in cancer patients. The formation of a stoma for colorectal cancer is a form of surgery which would be expected to cause considerable distress in the patient. However, there has been a limited amount of reliable research into this area (Greer & Silberfarb, 1982).

Surgical teams may be faced with a variety of difficult issues involving patients awaiting surgery such as, patients who experience severe pre-operative anxiety, patients who are unable to understand and give informed consent and individuals who may refuse to undergo surgery. Fortunately, pre-operative panic is relatively rare, reported to occur in less than 5% of surgical patients (Massie & Holland, 1987; Strain, 1985). It is most likely to occur in individuals with a pre-existing anxiety disorder (Jacobsen, Roth & Holland, 1998). There are also important considerations for individuals who take psychotropic medication which may require to be reduced in preparation for anaesthetic. This raises the possibility of exacerbating their psychiatric symptoms under the stressful conditions of impending surgery (Massie & Holland, 1987).

Acute post-surgical problems

It is important to differentiate between acute post-surgical problems and long term adjustment to surgical treatment. The immediate post-operative period involves recovery from the surgery and anaesthetic as well as confronting the physical changes to the body and in the case of stoma patients adaptation to the loss of bodily functioning (Jacobsen, Roth & Holland, 1998). O'Leary et al (2001) suggest that preoperatively, patients main concerns are the diagnosis of their cancer and the surgery and that it is not until afterwards that their attention fully focuses on the stoma. Some patients may refuse to look at their stoma during the first few days after their operation. Their thoughts in response to the stoma may provoke feelings of disgust, anger, embarrassment and shame. For some patients having an observable stoma violates their sense of cleanliness. When the colostomy first starts to work patients may report embarrassment at the noise and flatulence that is emitted. However, the general consensus is that improvements in patient care have resulted in less distress and better post-operative adjustment (Jacobsen, Roth & Holland, 1998; Oberst & James, 1985).

It is not uncommon for patients to develop acute confusional states such as delirium or cognitive disorders within the first few days of surgery. This is usually caused by effects of anaesthetic and medication, alcohol withdrawal, loss of circadian pattern and the stress of an unfamiliar environment, especially in the elderly (Jacobsen, Roth & Holland, 1998). Cancer patients may also develop major depression in the immediate post-operative period particularly when surgery is unsuccessful, the prognosis is poor or when surgery is known to cause sexual dysfunction (Jacobsen, Roth & Holland, 1998). Suicidal ideation may occur after surgery (Rosenberg, 1993) and needs to be carefully assessed in such patients (Jacobsen, Roth & Holland, 1998).

1.3 Long term effect of surgery on quality of life

During the last two decades advances in surgical techniques have led to sphincter conserving operations being carried out in preference to more radical surgery involving the formation of a stoma (Heald, 1980). As life expectancy increases this is likely to be accompanied by an increase in the number of individuals being treated for colorectal cancer (Devlin, 1994). Given that the mortality and morbidity rates are reported to be similar across the different surgical techniques used to treat colorectal cancer (Williams, 1984), an important question is how the different surgical techniques affect the patient's quality of life (Sprangers et al., 1995).

There is a vast body of literature which suggests that patients whose treatment for colorectal cancer results in a colostomy have a comparatively inferior quality of life than those without a colostomy (Camilleri-Brennan & Steele, 1998; Devlin, Plant & Griffin, 1971; Grundmann, Said & Krinke, 1989; Kuchenhoff et al., 1981; MacDonald & Anderson, 1985; Santangelo, Romano & Sassaroli, 1987; Schaube, Scharf & Herz, 1996; Sprangers et al., 1995; Williams & Johnston, 1983; Williams, Price & Johnston, 1980; Yeager & Van Heerden, 1980; Zieren et al., 1996). In a review of studies comparing long term effects of surgery for colorectal cancer, Sprangers et al (1995) found that both stoma and non-stoma patients report limitations across several domains of quality of life including physical, psychological, social and sexual functioning, while stoma patients were generally found to have a greater degree of impairment. More recently, researchers have failed to replicate these findings and have questioned these conclusions (e.g. Grumann et al., 2001).

In a recent study by Grumann et al (2001) quality of life was prospectively measured and compared across two groups of colorectal cancer patients, twenty three patients underwent

abdominoperineal resection resulting in permanent colostomy and fifty patients underwent anterior resection which did not require a colostomy. Quality of life was measured before surgery and then at six-to-nine-month and twelve-to-fifteen-month post-surgery intervals. Contrary to expectation, patients undergoing abdominoperineal resection resulting in a permanent colostomy tended to have a better quality of life across several quality of life domains, including physical, emotional, cognitive and social function, than patients whose anterior resection did not result in a colostomy (Grumann et al., 2001). The body image scale was the exception to these findings on which abdominoperineal patients scored less favourably. Interestingly, Grumann et al (2001) also found that there was a further distinction between quality of life among low and high anterior resection patients with low anterior resection patients displaying an inferior quality of life to both high anterior and abdominoperineal resection patients on certain domains. Although these results were not statistically significant Grumann et al (2001) emphasises the need for further investigation and explanations of such trends. Indeed, the rigorous inclusion criteria employed in this study may have restricted the number of patients who were eligible to participate resulting in a relatively small sample (Grumann et al, 2001). Despite that fact that these results contradict most of the findings of previous research studies, similar findings have been reported elsewhere. For example, Koller et al (1996) in a small-scale clinical study which compared quality of life between patients undergoing abdominoperineal resection and anterior resection found better quality in the former group.

In a study by Allal et al (2000) which compared quality of life in abdominoperineal patients and anterior resection patients following pre-operative radiotherapy, no significant differences in median scores were observed in any of the function scales studied which included physical, role, social, emotional and cognitive functions, as well as overall quality of life. Scores on physical function and overall quality of life scores were found to be higher

in the abdominoperineal resection group which also contradicts the findings of earlier studies (Allal et al., 2000). Although this study was well controlled in that patient groups were equally distributed in terms of age, WHO performance status, gender and median follow-up, areas which are often neglected in quality of life evaluation (Allal et al., 2000), the results of this study are limited in that it was a retrospective study. Patients whose surgery results in a temporary stoma are also said to suffer from impaired quality of life although this has been found to improve following the closure of the stoma (Wade, 1989). Several researchers have highlighted the need to consider carefully the possible methodological limitations of research in this area which may account for the considerable variance in findings (Camilleri-Brennan & Steele, 1998; McVey et al., 2001; Sprangers et al., 1995). This will be discussed in further detail at a later stage.

Physical functioning

Despite improvements in surgical methods used to treat colorectal cancer, patients may still have to cope with a variety of physical side-effects which may negatively impact on their quality of life. Cancer patients with or without a stoma report having diarrhoea, faecal leakage and frequency of bowel movement (Frigell, Ottander, Stenbeck et al., 1990; Karanjia, Schache & Heald, 1992; Lewis et al., 1992; Williams & Johnston, 1983). Although bowel function usually improves during the first year post surgery (Frigell, Ottander, & Stenbeck, et al, 1990), in some cases bowel problems remain beyond this (Lewis et al., 1992). Irregular or unpredictable bowel habits may lead to social isolation and can impair quality of life as patients may be afraid to leave their home or do certain activities due to fear of having an accident (Sprangers et al., 1995). Other physical symptoms commonly experienced by colorectal cancer patients include flatulence, urinary problems and disturbed sleep due to a disrupted and unpredictable bowel pattern (Sprangers

et al., 1995). Sprangers et al (1995) report that the degree to which these symptoms are experienced in stoma and non-stoma patients varies. For example, research has shown that stoma patients report more problems with gas and urinary function while non-stoma patients report more constipation (Baslev & Harling, 1983; Fegiz, Trenti & Bezzi, 1986; MacDonald & Anderson, 1984; Williams & Johnston, 1983). Grumann et al (2001) however reported that patients who had a permanent stoma reported less fatigue, gastrointestinal symptoms, sleeplessness, constipation and diarrhoea compared to patients who had undergone sphincter-conserving surgery. There is some evidence which suggests that stoma patients are more restricted in their diet than non-stoma patients (Devlin, Plant, & Griffin, 1971; Williams & Johnston, 1983) although, other investigations have failed to verify this finding (Frigell et al., 1990). Despite advances in stoma surgery and in stoma care it would appear that complications with stomas still arise (Abercrombie & Williams, 1995). Studies exploring the long term complications of colostomy have found that approximately 30% of patients develop a problem related to their stoma and that 10% of patients required at least one further surgical procedure to correct a complication (Fielding & Padmanabhan, 1994). Similar findings for patients with an ileostomy were reported by Leong et al (1994). It is not clear however if these particular studies refer specifically to colorectal cancer patients or whether the study sample consisted of patients with other diseases which require a stoma. Irrespective of this it is likely that there is some commonality in the complications faced by these different groups in relation to their stoma.

Social functioning

An early study by Devlin et al (1971) comparing patients who had undergone surgery resulting in the formation of a stoma with those who underwent sphincter-preserving surgery found that a high proportion of stoma patients experienced considerable social problems

relating to employment and social isolation. More recently Williams & Johnston (1983) also found that restriction of social activities was more common in patients following surgery resulting in a stoma than in non-stoma patients. This was mostly due to the presence of the colostomy which was reported to be a hindrance in doing leisure activities and caused considerable embarrassment. Some patients in this study reported avoiding certain activities due to fear of having an accident relating to their stoma. Numerous studies have reported on the adverse effect of abdominoperineal resection in relation to employment (Devlin et al, 1971). These results were replicated by Williams & Johnston (1983) who reported that patients commonly attributed this to having a colostomy especially when the type of work involved was manual. They found that those patients who did return to work often faced difficulties with their stomas which reportedly caused them to leave whereas non-stoma patients were more likely to return to work and remain in their job (Williams & Johnston, 1983). As Sprangers et al (1995) point out, the operational definition of social functioning used across studies varies considerably. It may include a variety of dimensions such as employment, frequency of social contacts, quality of relationships and restrictions in social activities due to the effect of illness or treatment (Sprangers et al., 1995). In a review of the research literature pertaining to social functioning Sprangers et al (1995) draw attention to the fact that several of the studies included in the review used unstandardised study specific questionnaires. It is also important to bear in mind the relevance of age on level of social activity and social network especially given that colorectal cancer patients are often older adults and may be restricted in their activities due to a general decline in physical health and the normal ageing process (Ferrell & Ferrell, 1998). In addition to this researchers have found that stoma patients tend to be older (Frigell, Ottander & Stenbeck, 1990; Williams & Johnston, 1983). Research suggests that while both stoma and non-stoma patients are restricted in their level of social activities, stoma patients are more confined in social activities and report a greater loss of interest in social activities compared to non-stoma

patients (McDonald & Anderson, 1985; Williams & Johnston, 1983; Wirsching, Druner & Hermann, 1975).

Psychological functioning

In a review of papers investigating psychological functioning in colorectal cancer patients, Sprangers et al (1995) concluded that psychological dysfunction was significantly more common in stoma patients as opposed to non-stoma patients. The category of psychological dysfunction employed by Sprangers et al (1995) encompassed depression, loneliness, suicidal thoughts, feelings of stigma, and low self-esteem. Although there was a considerable degree of overlap, these areas were significantly more prevalent in stoma patients than non-stoma patients (MacDonald & Anderson, 1984; Williams & Johnston, 1983; Wirsching, Druner & Hermann, 1975). The prevalence of anxiety, feelings of discomfort, and hopelessness was also higher in stoma patients although not significantly so (Frigell, Ottander, Stenbeck et al., 1990; MacDonald & Anderson, 1985; Wirsching, Drunmer & Herman, 1975). However, the definition of psychological functioning employed in these studies varied considerably in some cases unstandardised measures with unknown reliability and validity were used (Sprangers et al., 1995). Researchers have found that approximately 18-26% of patients who undergo surgery resulting in the formation of a stoma experience psychological difficulties during the first three months post surgery (Thomas, Madden & Jehu, 1984; Wade, 1990; White, 1995). Similar prevalence rates have been reported one year post surgery (Wade, 1990). It is suggested that these prevalence estimates are similar to those reported for patients who have undergone mastectomy surgery (Maguire et al., 1978) although estimated prevalence rates cited in the literature vary considerably with much higher prevalence rates also being reported (Druss, O'Connor & Stern, 1969; Keltikangras-Jarvinen, Loven & Moller, 1984). Interestingly the psychological

functioning of young female stoma patients was found to be more impaired in comparison to other groups such as older males (Sprangers et al., 1995). Initial depression was also reported as being highest among young and female stoma patients (MacDonald & Anderson, 1984). Careful consideration needs to be given to the methodological issues involved in these studies. The assessment of depression in cancer patients is hindered in that many scales used to measure depressive symptomatology include items relating to tiredness, loss of appetite and sleep disturbance all of which may be symptoms of the cancer itself or side-effects of treatment (Greer & Silverfarb, 1982). Irrespective of the possible methodological shortcomings of the research literature in this area it is important to be aware that psychological difficulties are likely to compromise a patient's recovery post-surgery (White & Hunt, 1997).

Body image

Research suggests that perceived physical integrity is important in understanding psychological adjustment to illness and treatment involving altered body form (e.g. Faulkener & McGuire, 1994). It is well documented that cancer patients who have undergone mutilating surgery often experience body image problems (Fallowfield, 1991; Sims, 1988). To date most of the research carried out in this area has focused on breast cancer with a comparatively limited amount of attention being paid to other cancers (Hopwood, Fletcher, Lee & Ghazal, 2001). Body image has been increasingly recognised as an important component in assessment of quality of life when comparing mastectomy and breast conserving surgery (Hopwood et al., 2001). One would expect that this would equally apply to the treatment used in colorectal cancer which also involves body altering surgery. Sims (1988) emphasises that body image problems not only occur from the loss of a body part or from disfigurement but may also arise in response to the loss of a body function. This

particularly applies to patients who have undergone surgical treatment for colorectal cancer involving the formation of a stoma (Sims, 1988). Numerous studies have reported that colorectal cancer patients who undergo colostomy surgery report body image disruption, disfigurement, embarrassment and secondary isolation (Grundmann, Said & Krinke, 1989; Keltikangas-Jarvinen, Loven &Moller, 1984; Kirkpatrick, 1980; MacDonald & Anderson, 1984; MacDonald & Anderson, 1985). In an early study of the impact of surgery for colorectal cancer Devlin, Plant & Griffin (1971) found that patients commonly reported a changed body concept, feeling freakish, and the sensation of phantom rectum. In a study by Williams and Johnston (1983), they reported a highly significant difference in the measurement of deterioration in body image of stoma patients compared to non-stoma patients, with stoma patients reporting a higher level of distress in relation to appearance and change in body image. In a recent study by Grumann et al (2001) both stoma and non-stoma colorectal cancer patients showed a similar pattern of deterioration in body image although this was less pronounced in non-stoma patients. It was suggested that the body image disturbance in stoma patients was likely to be attributable to the presence of their colostomy and the process of acceptance and adjustment while the body image disturbance in patients without a colostomy may have been due to the commonly reported post-operative increase in defecation problems (Camilleri-Brennan & Steele, 1998; Williams & Johnston, 1983). However, as Sims (1988) cautions, there has been a lack of reliable investigation into this area. Hopwood (1992) points out that there are conceptual and methodological difficulties in measuring body image in view of the fact that it is not a distinct concept. Derogatis (1986) shares this view when he describes body image and sexual functioning as overlapping dimensions which are integrally related components of self-image and psychological adjustment. This may to some extent account for the variability with which body image is assessed across different studies, which at times leads to inconsistent findings (Fallowfield, 1990).

Sexual functioning

An important area of investigation relevant to quality of life is that of sexual functioning. Several authors have reported on the potentially negative impact of cancer treatment on sexual functioning (Allal et al., 2000; Grumann, 2001; Halifan, Althausen, Goldstein et al., 1990; Moyer & Salovey, 1997; Sprangers et al., 1995). Deterioration in sexual functioning may be the result of medical treatment, psychological factors or a combination of both. There is considerable variance in the prevalence estimates of sexual problems among colorectal cancer patients cited in different studies (Sprangers et al., 1995). The first year after cancer treatment is the most likely time for most sexual dysfunctions caused by cancer therapy to appear (Schover, 1998). Anxiety and worry about resolving these problems may also arise as people begin to return to their normal routine of daily living and recover from their illness (Schover, 1998).

There are numerous reports that the surgical procedures used to treat colorectal cancer, namely abdominoperineal resection and low anterior resection, may result in damage to pelvic nerves which lead to the genitals, therefore resulting in impaired sexual functioning (Sprangers et al., 1995). The incidence of sexual dysfunction is said to be more likely with more extensive operations (Mannaerts et al., 2001). In female patients these operations allow for most of the nerve supply to be conserved, in theory, allowing women to maintain sexual functioning (Weinstein & Roberts, 1977). The types of sexual problems most commonly found in patients following these operations include erectile dysfunction in male patients and pain during sexual intercourse, known as dyspareunia, in female patients (Schover, 1998). In male patients loss of erectile capacity may be accompanied by loss of fertility (Schover, 1998).

Several authors have concluded that the prevalence of sexual dysfunction is higher among stoma patients compared to patients whose surgical treatment did not involve the formation of a stoma (e.g. Allal et al., 2000; Finlay & McArdle, 1986; Grumann et al., 2001; Machi, Isomoto & Kurohiji, 1991; Machi & Sigel, 1989; Masters, Steger, & Brown, 1991). Allal et al (2000) reported that sexual functioning was low for both groups included in their study while there were notably high scores in relation to sexual dysfunction in males although statistical significance was not achieved.

Surgery may also cause sexual dysfunction indirectly through side-effects. For example, post-operative pain is related to problems relaxing and in enjoying physical intimacy. Similarly, negative body image and bowel problems are likely to affect feelings of sexual desirability and confidence (Moyer & Salovey, 1997).

Radiotherapy has been reported to increase the likelihood of damage being caused to the urogenital nerves and organs also resulting in impairment of sexual functioning (Mannaerts et al., 2001). It also contributes to fatigue and loss of libido which may indirectly disrupt sexual functioning in the first year or so following surgery (Schover, 1991). Chemotherapy may also impact on sexual functioning through physical side-effects such as fatigue and nausea which are likely to reduce sexual interest, as well as more psychological reasons such as loss of hair which may make the patient feel less attractive (Halifin, Althausen, Goldstein et al., 1990).

Sexual dysfunction may occur for reasons other than surgical treatment and adjuvant therapy. Loss of sexual desire is also commonly reported in both males and females after treatment for cancer (Schover, 1998). This is sometimes related to specific cancer treatment but may also be related to difficulties with psychological adjustment (Schover, Montague &

Schain, 1993). Depression and anxiety are known to have a negative impact on sexual functioning (Teusch, 1995). Researchers investigating sexual functioning in cancer patients have found a relationship between sexual dysfunction and poor individual or couple psychological adjustment (Gritz et al., 1989; Schover, Evans, & von Eschenbach, 1987).

Sexual functioning is also determined by a range of variables. For example, premorbid sexual functioning is likely to be highly relevant and may predict sexual function after treatment (Schover, 1998). It is important to consider the relevance of age when discussing the impact of treatment on sexual functioning among colorectal cancer patients (Koukouras et al, 1991; MacDonald & Anderson, 1984). Given that the majority of colorectal cancer patients are aged between sixty and seventy years of age their level of sexual interest and sexual capacity may well have declined due to life stage independent of the effects of treatment. As age increases there is also the increased likelihood that the patient's partner may have died and therefore they may no longer be sexually active. It is therefore necessary to bear in mind the significance of age range and average age of samples used in studies reporting on sexual functioning. In a study by Koukouras et al (1991), despite stratification procedures being used to control for age, the study supported the conclusion that sexual functioning is more impaired in patients with a stoma. Other factors which may affect sexual functioning include tumour size, extent of tumour spread at the time of surgery and the patient's general physical health (Danzi et al., 1983). There are methodological issues which may account for some of the variability in prevalence estimates of sexual dysfunction reported in the research literature (Sprangers et al., 1995). For example, definitions of sexual function or dysfunction employed in studies are variable and are likely to contribute to a diverse range of findings.

Recurrence of cancer

Unfortunately, in some cases patients may experience a recurrence of the cancer. It is suggested that this is likely to be more distressing than the initial diagnosis (Mahon, Cella & Donovan, 1990; Silberfab, Maurer & Crouthamel, 1980) which is unsurprising given the negative implications for longer term survival. Spencer, Carver & Price (1998) suggest that for individuals facing news that their cancer has returned adjustment to the new diagnosis also involves facing the possibility of having a more limited future.

Factors influencing psychological response to stoma surgery

Surgery resulting in the formation of a stoma requires a considerable degree of psychological adjustment (Devlin, Plant & Griffin, 1971; Wirsching, Druner & Herman, 1975). There is considerable variance in the degree and nature of individuals' psychological responses to surgery (Bradley, 1982). The research literature suggests that a variety of factors, including characteristics of the individual, characteristics of the particular form of surgery and more generally the characteristics of the health care system in which treatment is delivered, may determine the response of an individual to surgery (Kincey, 1995). Relevant factors can also be categorised according to pre and post operative factors (White & Hunt, 1996).

An extensive review of the literature pertaining to the psychological factors determining post-operative adjustment to stoma surgery was carried out by White & Hunt (1996). Previous psychiatric history, pre-operative preparation, physical symptoms and illness related beliefs were identified as being relevant factors (White & Hunt, 1996). The majority of studies in this review related to stoma surgery in colorectal cancer although other illnesses were included.

Psychiatric history

Several studies have concluded that past psychiatric history is associated with increased post-operative psychological morbidity (e.g. Thomas, Madden & Jehu, 1987; Wade, 1989; White & Unwin, 1998; Wirsching, Durner & Hermann, 1975).

Pre-operative psychological preparation

There is evidence to suggest that psychological preparation prior to surgery facilitates post-operative emotional adjustment and recovery (Jacobsen, Roth & Holland, 1998). The perceived adequacy of pre-operative preparation has been found to be significantly associated with psychological morbidity following stoma surgery (Follick, Smith & Turk, 1984; Thomas et al., 1987b; Wade, 1989).

Physical symptoms

Individuals who experience post-operative physical complications or physical symptomatology relating to their stoma appear to have more psychological problems (Oberst & Scott, 1988; Thomas et al., 1987b; Wade, 1990)

Cognitions

Sensky (1990) suggests that there is compelling evidence that cognitive factors explain more of the variability in psychosocial adjustment to illness than disease-related variables. In a study by White & Unwin (1998) investigating the role of stoma related cognitions they reported that cognitive factors did significantly contribute to the variance in post-operative

psychological adjustment. These conclusions are supported by other researchers (e.g. Bekkers et al., 1996).

Positive and negative consequences of surgery

There are several other factors, not included in White & Hunt's review which have been linked to post-operative adjustment which may also apply to stoma surgery. For example, Kincey & Saltmore (1988) suggest that variance in psychological outcome following surgery may be attributable to the balance which exists between the positive and negative consequences of a particular form of surgery. The sphincter-conserving and sphincter - sacrificing surgical procedures used in the treatment of colorectal cancer have advantages and disadvantages. For example, it may improve bowel functioning and is likely to reduce subsequent mortality and morbidity but may result in sexual dysfunction, deterioration in body image (Sprangers et al., 1995), and increased self-care demands, particularly if the operation results in the formation of a stoma (White & Unwin, 1998).

Individual coping responses

Coping responses reported by cancer patients are diverse (Spencer, Carver & Price, 1998). Coping approaches described by cancer patients as being beneficial include using emotional support resources, confronting the situation head on, seeking information, having a positive attitude, having a fighting spirit and seeking comfort from religious faith (Spencer, Carver & Price, 1998). Such coping methods are associated with lower distress (Burgess, Morris & Pettingale, 1988; Felton & Revenson, 1984; Felton, Revenson & Hinrichsen, 1984; Nelson et al., 1989;) and better social functioning (Bloom & Spiegel, 1984; Watson, Greer & Rowden, 1991). Less effective coping methods include adopting a fatalistic or helpless attitude (Halstead & Fernsler, 1994), while avoidant coping methods such as denial or self

blame are associated with higher levels of distress (Carver, et al., 1993; Felton & Revenson, 1984).

While several factors which have been thought to predict psychological adjustment to surgery have been investigated, most of the research has failed to consistently identify specific variables which account for the variance in postoperative adjustment to stoma surgery (Bekkers, van Knippenberg, van den Borne, Bergsma & van Berge Henegouwen, 1995).

1.4 Limitations of studies comparing quality of life in stoma versus non-stoma colorectal cancer patients

There has been a lack of reliable research into the effects of colorectal cancer surgery on long term quality of life (McVay et al., 2001). A number of methodological issues have been identified which limit the value of some studies in this area (McVey et al., 2001). These include small sample sizes, the use of unstandardised measures, variation in period of time elapsed since surgery at which quality of life is measured and the inconsistent use of quality of life domains measured (McVey, 2001, Sprangers et al., 1995). In some studies, samples have consisted of patients with different disease stages who have undergone different treatment procedures (McVey, 2001). Other studies have included patients who have diseases other than cancer which have led to the formation of their stoma and may involve different types of stomas (e.g. White & Unwin, 1998). Many studies have used cross-sectional designs rather than prospective designs.

Several studies have found that patients post-operative levels of psychological distress vary over time (e.g. Morris, Greer & White, 1977) and therefore caution should be taken in drawing conclusions from only one follow-up as this may not be representative of the person's psychological status at a later date. Many studies have failed to take into account the presence of clinically significant psychological morbidity pre-diagnosis and pre-surgery when assessing the prevalence of psychological difficulties post-surgery (e.g. Devlin, Plant & Griffin, 1971; Druss et al., 1968; Druss, O'Connor & Stern, 1969; Keltikangras-Jarvinen & Jarvinen, 1987; Keltikangas-Jarvinen, Loven & Moller, 1984; Klopp, 1990). Using only a measure of post-operative psychological symptomatology does not allow for changes in level of distress to be accounted for over time.

1.5 Aims and objectives of current investigation

Aim:

The aim of the current study was to explore long-term quality of life in patients who have undergone surgery for colorectal cancer.

Objective:

To evaluate the impact of surgery resulting in the formation of a stoma on long-term quality of life.

1.6 Hypothesis

It was hypothesised that sphincter-conserving surgery as opposed to sphincter-sacrificing surgery would result in better long-term quality of life, as indicated by global quality of life, physical, social, psychological and sexual functioning, body image, and degree of illness/treatment symptoms, at twelve to eighteen months post-surgery.

2. Method

2.1 Design

Study design

Long-term quality of life was investigated in a study of patients previously treated for colorectal cancer. Patients were interviewed at an interval of between twelve and eighteen months post-surgery using measures to assess quality of life and level of psychological distress. These measures were used to compare patients who had undergone sphincter-conserving surgery versus patients who had undergone sphincter-sacrificing surgery resulting in the formation of a stoma. A between subjects study design was used and the level of correlation between measures was explored.

Calculation of statistical power/expected effect size

A minimum sample of 80 participants was calculated as being required for the study in order to achieve sufficient statistical power to demonstrate moderate effect sizes at the 0.8 level (Cohen, 1988). Fewer participants were recruited than was anticipated.

Sample

A total sample of 32 participants were included in this study consisting of patients who under went sphincter-conserving surgery (n=21) and patients who underwent sphincter-sacrificing surgery resulting in a permanent stoma (n=11). Information relating to general health status, type of disease, disease stage, type of surgery and other adjuvant therapy received was obtained from medical case notes. Demographic information including age,

marital status and employment was also recorded. The characteristics of the study sample are presented below in Table 2.1.

Table 2.1: Patient demographic details and information on disease/treatment variables.

	Non-stoma	Stoma	Total
Gender			
Male	15 (71%)	8 (73%)	23 (72%)
Female	6 (29%)	3 (27%)	9 (28%)
Age			
Mean	65.90	65.91	65.91
S.D.	11.70	10.61	11.16
Range			35 to 84 years
Marital status			
Married	16 (76%)	5 (45 %)	21 (66%)
Single	1 (5%)	0	1 (3%)
Widowed	4 (19%)	6 (55%)	10 (31%)
Separated or divorced	0	0	0
Living with partner	0	0	0
Have partner but not cohabiting	0	0	0
Employment status			
Working full-time	3 (14%)	2 (18%)	5 (16%)
Working part-time	1 (5%)	0	1 (3%)
Unemployed	2 (10%)	1 (9%)	3 (9%)
Retired	14 (67%)	7 (64%)	21 (66%)
Sick benefit	0	1 (9%)	1 (3%)
Not working for other reasons	1 (5%)	0	1 (3%)
Detected by screening programme	9 (43%)	2 (18 %)	11 (34%)
Emergency operation	1 (5%)	4 (36%)	5 (16%)
Adjuvant therapy			
Radiotherapy (pre-op)	0	2 (18%)	2 (6%)
Chemotherapy (post-op)	6 (29%)	3 (27 %)	9 (28%)
Number of months post operation			
Mean	14.38	12.91	13.89
S.D.	1.77	1.58	1.83
Range			12 to 17 months.

2.2 Procedure

Patient ethics

Ethical approval was obtained from Fife Health Board Ethics Committee prior to starting the study.

Patient recruitment

Participants were recruited from lists supplied by the Fife Area Laboratory Histopathology Department, of patients who had undergone surgery for colorectal cancer at Queen Margaret Hospital, Dunfermline or Victoria Hospital, Kirkcaldy. There were approximately 150 patients on the original list who were eligible for participation in this study in terms of their surgical treatment. The sample used was selected from this list having met the inclusion criteria for the study. All patients who were considered for inclusion in the study had undergone surgical treatment between twelve and eighteen months previously.

Study inclusion/exclusion criteria

Patients were contacted about the study after their general practitioner and colorectal cancer surgeon had been consulted regarding the researchers intention to contact them. Patients were considered to be eligible for the study if they were eighteen years of age, had been given a diagnosis of colorectal cancer, had undergone surgical treatment within the last twelve to eighteen months, their operation was with curative intention and they had no known recurrent disease and were well enough at the time of interview. Patients with known evidence of cognitive impairment or severe mental illness were excluded from the study.

Patient consent

Written, informed consent was obtained from patients before they entered the study. Patients were advised that their decision whether or not to participate in the study would not affect their treatment in any way and that they were free to withdraw from the study at any time without giving a reason. Potential participants were sent a patient information sheet and covering letter (see Appendix 1) providing details of the study at least one week before being contacted by telephone and asked if they would be willing to participate.

Research interview

Interviews were conducted either at an out-patient clinic or at the patient's home, dependent on availability of clinic space and whether the patient had transport. The interview lasted approximately one hour.

2.3 Measures

Copies of all measures used in the study are included in Appendix 2.

Hospital Anxiety and Depression Scale (HADS)

The Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) is a fourteen item scale which provides a brief state measure of anxiety and depression. The HADS is a well-validated clinical research scale, designed for use in medical out-patient clinics, which does not include items that may be confused with physical symptoms related to illness. Anxiety and depression are measured on two separate sub-scales each consisting of seven items, with each item scored from 0 to 3, so that the total score for each sub-scale ranges from 0 to 21. A score on either sub-scale from 8 to 10 indicates a possible clinical disorder and a score of 11 and above is the cut-off for probable clinical levels of anxiety or depression. Mean anxiety and depression sub-scale scores have been reported for a clinical population of 573 patients with cancer at the time of initial diagnosis or first recurrence (Moorey et al., 1991).

Body Image Scale (BIS)

Body image was examined using the 10-item Body Image Scale (BIS; Hopwood, Fletcher, Lee & Ghazal, 2001) constructed in collaboration with the EORTC Quality of Life Study Group. It was designed to be used in conjunction with other quality of life measures and as a specific scale to assess body image as a psychosocial outcome measure in clinical treatment trials. The Body Image Scale (BIS) was used to provide a measure of body image satisfaction following treatment. Responses to each item on the scale are rated on a 4 point Likert scale (0=not at all, 1= a little, 2 = quite a bit, 3=very much). The ten items are then summed to produce an overall summary score for each patient, ranging from 0 to 30. Zero scores represent no symptoms/distress and higher scores represent increasing

symptoms/distress. The BIS was designed for use with any cancer patient group likely to experience body image concerns as a result of their disease or its treatment. The BIS was validated on a sample of 276 cancer patients. This included a sub-sample of colorectal cancer patients (n=37, 13%) treated by a combinations of surgery and chemotherapy or radiotherapy. The scale was found to demonstrate high reliability and good clinical validity based on response prevalence, discriminant validity, sensitivity to change and consistency of scores across different cancer treatment centres (Hopwood, Fletcher, Lee & Ghazal, 2001). The scale was designed so that it could be used with any cancer patient group likely to experience body image concerns (Hopwood, Fletcher, Lee & Ghazal, 2001).

Quality of life: European Organization for Research and Treatment of Cancer (EORTC QLQ-30) Colorectal Cancer-specific Quality of Life Questionnaire (QLQ-CR38).

Quality of life was measured using the European Organization for Research and Treatment of Cancer (EORTC) quality of life questionnaire QLQ-30 (Aaronson et al., 1993) and the complementary colorectal cancer specific module QLQ-CR38. The QLQ-30 is a patient self-rating questionnaire which was designed to assess a range of health related quality of life issues relevant to a range of cancer patients. It consists of thirty items comprising six function scales measuring physical, role, social, emotional and cognitive functions, and overall quality of life, as well as symptom scales assessing pain, fatigue, emesis, bowel function, dyspnoea, appetite loss and sleep disturbance. A final item evaluates the perceived economic impact of the disease. The QLQ-C30 has been used to measure quality of life for almost two decades in various samples of cancer patients (Bjordal et al., 1999; Koller et al., 1996; Zieren et al., 1996).

The QLQ-CR38 is designed for use with a wide range of colorectal cancer patients, varying in disease stage and treatment modality. It consists of 38 items assessing disease symptoms, side-effects of treatment (including sphincter-conserving surgery, sphincter-sacrificing surgery, radiotherapy and chemotherapy), body image, sexuality and future perspective. The first 19 questions are completed by all patients and the remaining questions are completed by subsets of male/female patients and stoma/non-stoma patients. This module has been validated in a study in the Netherlands and is currently being used in a wide range of cross-cultural studies (Sprangers et al., 1999).

Both of these measures are well-established tools for the assessment of quality of life in patients with cancer (Grumann et al., 2001) and have been proven to be reliable and valid (Aaronson et al., 1994; Sprangers et al 1999). All sub-scale scores are converted to a score out of 100, range 0 to 100, using linear transformation. The higher scale score represents a higher level of functioning for the six QLQ-C30 and four QLQ-CR38 multi-item/single function scales and a higher level of symptomatology/problems for the symptom/single item scales (Allal et al., 2001).

3. Results

Statistical analysis of results

The data collected at interviews was analysed using the Statistical Package for the Social Sciences (SPSS) version 11. The data was checked for anomalies such as extreme values and skewed distributions prior to analysis. Although extreme values and outliers were identified in some of the sub-sets of data these cases were retained in the analysis. This decision was based on careful examination of the cases identified as extreme values which were judged to be representative of important clinical information for that particular participant. It was therefore deemed that to remove these data entries would distort the clinical accuracy of conclusions drawn from the results of the analysis. Missing values were assigned a numerical value which excluded these values from the statistical analysis but allowed missing data to be easily identified. Moinpur et al (2000) highlight the need to inform readers about the extent of missing data in any study and to note its presumed effect on conclusions about the effects of treatment on quality of life. Statistical analysis was carried out using descriptive statistics, independent samples t-tests, independent samples Mann-Whitney tests, Pearson correlation and univariate analysis of variance. Statistical significance was accepted at the 0.05 level.

Influence of other factors on long term quality of life

Age

An independent samples t-test showed that there was no significant difference in age between patients who underwent sphincter conserving (SC) surgery and those who underwent sphincter sacrificing (SS) surgery resulting in a stoma, $t(30)=-0.001$; $p=0.999$, $p>0.05$.

Length of post-operative period of recovery

An independent samples t-test indicated that there was a significant difference between the two groups in the number of months that had elapsed since surgery at the time of interview, $t(30)=2.311$; $p=0.028$, $p<0.05$. The effect of time elapsed since surgery on results was examined using univariate analysis of variance. A significant effect was found between the number of months post operation and sexual functioning, $F(1,28)=6.854$; $P<0.05$, indicating that stoma patients had a significantly lower number of months since their operation which was associated with poorer sexual functioning. No other significant covariate effects were found on any other variables.

3.1 Main results

Global Health Status Quality of life

Mean scores obtained on the global health status quality of life sub-scale of the EORTC QLQ-C30 and the results of an independent samples t-test are shown below in table 3.1. This sub-scale is based upon a rating of overall health and overall quality of life during the past week. No significant difference was found between stoma and non-stoma patients $t(30)=1.388$; $p>0.05$.

Table 3.1: EORTC QLQ-C30 global health related quality of life sub-scale mean scores and results of independent samples t-test.

Type of surgery [1]	Mean score [2]	S.D.	t	df	Sig. (2-tailed) Sig (*p<0.05)
SC (n=21)	86.48	16.62	1.388	30	0.175 n.s
SS (n=11)	76.45	24.00			

[1] SS=sphincter conserving SS=sphincter sacrificing

[2] A high score represents a high quality of life.

Physical functioning

Mean scores obtained on the physical functioning sub-scale of the EORTC QLQ-C30 and the results of an independent samples t-test are shown below in table 3.7. This sub-scale included questions relating to difficulty experienced in doing strenuous activities, taking a long or short walk and level of assistance required with daily activities of self-care such as eating dressing washing. There was no significant difference between stoma and non-stoma patients in reported level of physical functioning, $t(30)=0.175$; $p>0.05$.

Social functioning

Mean scores obtained on the social functioning sub-scale of the EORTC QLQ-C30 and the results of an independent samples t-test are shown below in table 3.7. This sub-scale included questions relating to the extent to which the individual's physical condition or medical treatment had interfered with their family life and with their social activities. No significant difference was found in the level of social functioning between stoma and non-stoma groups $t(12)=1.712$; $p>0.05$. Levene's test for equality of variances indicated that the p-value for F was greater than 0.05 therefore, equal variances were not assumed and results are reported accordingly.

Psychological functioning

Mean scores and results of independent samples t-tests for the emotional functioning sub-scale of the EORTC QLQ-C30 are shown below in table 3.7 and the HADS tables 3.3 and 3.4. There was no significant difference between the stoma and non-stoma group on the EORTC QQC-30 emotional functioning sub-scale $t(30)=0.480$; $p>0.05$. This sub-scale consisted of two items relating to anxiety and two items relating to depression. These findings are consistent with the results of independent t-tests for the anxiety and depression sub-scales of the HADS $t(30)=0.235$; $p>0.05$ and $t(30)=0.498$; $p>0.05$, respectively. Amongst the sample of patients with a stoma, one participant had a score which fell within the cut-off range for possible clinical disorder (HADS 8-10). However, no-one obtained a score indicating a probable clinical level of anxiety (HADS =>11). Amongst the group of patients with no stoma one participant obtained a score indicating a probable clinical level of anxiety (HADS >11) while two participants' scores fell within the cut off range of a possible clinical level of anxiety (HADS 8-10). No participants in either group had a clinically significant score on the HADS depression scale (HADS =>11).

Table 3.2: HADS anxiety sub-scale mean scores and results of independent samples t-test.

Type of surgery [1]	Mean score	S.D.	t	df	Sig. (2-tailed) Sig (*p<0.05)
SC (n=21)	3.29	3.48	0.235	30	0.816 n.s.
SS (n=11)	3.00	2.79			

[1] SS=sphincter conserving SS=sphincter sacrificing

Table 3.3: HADS depression sub-scale mean scores and results of independent samples t-test.

Type of surgery [1]	Mean score	S.D.	t	df	Sig. (2-tailed) Sig (*p<0.05)
SC (n=21)	1.86	2.20	0.498	30	0.622 n.s.
SS (n=11)	2.27	2.33			

[1] SS=sphincter conserving SS=sphincter sacrificing

Body image

Mean scores and results of independent samples t-tests for the body image sub-scale of the EORTC QLQ-CR38 and the BIS are shown below in tables 3.7 and 3.4. The EORTC QLQ-CR38 body image sub-scale consists of two items relating to the extent to which the individual has felt less masculine/feminine as a result of their disease or treatment and the extent to which they have been dissatisfied with their body. Levene's test for equality of variances indicated that the p-value for F was greater than 0.05 therefore, equal variances were not assumed. A significant difference was identified between the two groups on the body image measure $t(14) = 2.899$; $p<0.05$. This is consistent with the results of the independent samples t-test of the Body Image Scale BIS, $t(11)=3.462$; $p<0.05$. These results indicated that the group of stoma patients were significantly more dissatisfied with their body image than patients without a stoma.

Table 3.4: BIS mean scores and results of independent samples t-tests.

Type of surgery [1]	Mean score	S.D.	t	df	Sig. (2-tailed) Sig (*p<0.05)
SC (n=21)	1.57	3.12	2.484	30	0.019 *
SS (n=11)	4.64	3.67			

[1] SS=sphincter conserving SS=sphincter sacrificing

Sexual functioning

Mean scores and the results of independent samples t-tests for the sexual functioning and sexual enjoyment, sub-scales of the EORTC QLQ-CR38 are shown below in table 3.7 and table 3.5 respectively. Results of a Mann-Whitney test is shown below in table 3.8 for the EORTC QLQ-CR38 male sexual problems sub-scale. The sexual functioning sub-scale consisted of two items relating to level of interest in sex and extent of sexual activity during the previous four week period. Rating of sexual enjoyment was only given if respondent had been sexually active during the last four weeks. For males the sexual problems sub-scale consisted of items relating to difficulty getting /maintaining an erection and problems with dry ejaculation. For females sexual problems included having a dry vagina or pain during intercourse. Statistical analysis of female sexual problems was not appropriate due to the low numbers reported for this sub-scale (n=2). No significant difference was found between the stoma and non-stoma groups in their rating of sexual functioning and rating of sexual enjoyment, $t(29)=1.453$; $p>0,05$, and $Z=0.990$; $p>0.05$. Responses to the sexual enjoyment scale were only available for 5 out of 11 (45%) stoma patients and for 13 out of 21 non-stoma patients (62%). No significant difference was found between stoma and non-stoma patients in terms of female sexual problems, $t(2)=0.816$; $p>0.05$. A significant difference was found on the male sexual problems sub-scale, $t(7.578)=2.291$; $p=0.05$, indicating that

male stoma patients experience significantly more sexual problems than males without a stoma. Levene's tests for the equality of variances indicated that the p value for F was significant therefore equal variances were not assumed for the male sexual problems sub-scale and results have been reported accordingly.

Table 3.5: EORTC QLQ-CR38 sexual enjoyment sub-scale results of Mann-Whitney test.

Type of surgery [1]	Mean rank	Sum of ranks	Z	Sig. (2-tailed) Sig (*p<0.05)
SC (n=13)	10.23	133.00	0.990	0.322 n.s
SS (n=5)	7.60	38.00		

[1] SC=sphincter conserving SS=sphincter sacrificing

Cognitive functioning

The cognitive functioning sub-scale of the EORTC QLQ-C30 contained two items related to concentration and memory. No significant difference was found between stoma and non-stoma patients on the cognitive functioning $T(30)=0.157$; $p>0.05$. Mean scores and the results of an independent samples t-test are reported below in table 3.7.

Role functioning

The role functioning sub-scale of the EORTC QLQ-C30 is based on ratings of the extent to which the individual was limited in doing either work or daily activities and in pursuing hobbies and leisure time activities. No significant difference was found between the two groups on the role functioning sub-scale $t(11.962)=1.868$; $p>0.05$. Mean scores and results of an independent samples t-test are reported below in table 3.7.

Future perspective

The future perspective sub-scale of the EORTC -CR38 is based on one item relating to the extent that individuals were worried about their health in the future. There was no significant difference found between the stoma and non-stoma group on the future perspective sub-scale $z=0.495$; $p>0.05$. Results of a Mann-Whitney test are reported below in table 3.6.

Table 3.6: EORTC QLQ-CR38 future perspective sub-scale results of Mann-Whitney test.

Type of surgery [1]	Mean rank	Sum of ranks	Z	Sig. (2-tailed) Sig (*p<0.05)
SC (n=21)	15.95	335.00	0.495	0.621 n.s
SS (n=11)	17.55	193.00		

[1] SC= sphincter conserving SS= sphincter sacrificing

Table 3.7: EORTC QLQ-C30 and QLQ-CR38 functional scales mean scores and results of independent samples t-tests.

Scale	Type of surgery [1]	Mean score [2]	S.D.	t	df	Sig. (2-tailed) Sig(*p<0.05)
Physical	SC (n=21)	91.43	20.56	0.175	30	0.862n.s
	SS (n-11)	92.73	18.49			
Role	SC (n=21)	96.05	10.34	1.868	11.962	0.086n.s
	SS (n-11)	81.82	24.12			
Emotional	SC (n=21)	84.29	17.21	0.480	30	0.635 n.s
	SS (n-11)	87.81	14.05			
Cognitive	SC (n=21)	88.81	18.57	0.157	30	0.876 n.s
	SS (n-11)	87.82	13.04			
Social	SC (n=21)	97.57	6.10	1.712	11.656	0.113 n.s
	SS (n-11)	89.27	15.46			
Body image	SC (n=21)	94.76	10.79	2.899	13.517	0.012*
	SS (n-11)	76.91	18.88			
Sexual	SC (n=21)	26.65	23.23	1.453	29	0.157 n.s
	SS (n-11)	15.00	17.23			

[1] SC= sphincter conserving SS= sphincter sacrificing

[2] A high score represents a high level of functioning

Symptom scales

On all symptom scales a high score represents a high level of symptomatology.

Gastrointestinal symptoms

Mean scores obtained on the gastrointestinal symptoms sub-scale of the EORTC QLQ-CR38 and the results of an independent samples t-test are shown below in table 3.8. There was no significant difference between stoma and non-stoma patients in terms of reported gastrointestinal symptoms $t(30)=0.242$; $p>0.05$.

Fatigue

No significant difference was found between the stoma and non-stoma group on the fatigue sub-scale of the EORTC QLQ-C30 $t(30)=0.48$; $p>0.05$. Mean scores and results of an independent samples t-test are reported below in table 3.8.

Pain

No significant difference was found between the stoma and non-stoma groups on the pain sub-scale of the EORTC QLQ-C30, $t(30)$; $p>0.05$. Mean scores and the results of an independent t-test are reported in table 3.8 below.

Micturition problems

Micturition problems relates to frequency and pain in terms of urination. Mean scores and results of an independent samples t-test for the micturition sub-scale of the EORTC QLQ-CR38 are reported below in table 3.8. There was no difference between the stoma and non-stoma group on the micturition sub-scale, $t(30)= 0.824$; $p>0.05$.

Table 3.8: EORTC QLQ-C30 and CR38 symptom scales results of independent samples t-tests.

Scale	Type of surgery [1]	Mean score [2]	S.D.	t	df	Sig.(2-tailed) Sig (*p<0.05)
Fatigue	SC (n=21)	13.67	25.38	0.48	30	0.962 n.s
	SS (n=11)	14.09	19.33			
Pain	SC (n=21)	8.71	22.54	0.577	30	0.568 n.s
	SS (n=11)	4.55	10.73			
Micturition	SC (n=21)	15.19	13.68	0.824	30	0.417 n.s
	SS (n=11)	20.09	19.80			
Gastrointestinal symptoms	SC (n=21)	12.67	11.91	0.242	30	0.810 n.s
	SS (n=11)	11.55	13.40			
Male sexual problems	SC(n=12)	12.50	21.49	2.291	7.578	0.053*
	SS (n=7)	54.57	45.72			

[1] SC= sphincter conserving SS=sphincter sacrificing

[2] A high score represents a high level of symptomatology

Dyspnoea

The dyspnoea sub-scale consisted of one item relating to breathlessness. No significant difference was found between the stoma and non-stoma groups on the dysponea sub-scale of the EORTC QLQ-C30, Z=0.212; p>0.05.Results of a Mann-Whitney test are reported below in table 3.9.

Insomnia

No significant difference was found between stoma and non-stoma patients on the insomnia item of the EORTC QLQ-C30, Z=1.702; p>0.05. Results of a Mann-Whitney test are reported below in table 3.9.

Appetite loss

There was no significant difference between stoma and non-stoma patients on the appetite loss sub-scale of the EORTC QLQ-C30, $Z=0.473$; $p>0.05$. Results of a Mann-Whitney test are shown below in table 3.9

Constipation

Results of a Mann-Whitney test for the constipation sub-scale of the EORTC QLQ-C30 are shown below in table 3.9. There was no significant difference between the stoma and non-stoma group, $Z=0.725$; $p>0.05$.

Diarrhoea

There was no significant difference between the stoma and non-stoma groups on the diarrhoea sub-scale of the EORTC QLQ-C30, $Z=1.221$; $p>0.05$. The results of a Mann-Whitney test are shown below in table 3.9.

Financial difficulties

Results of a Mann-Whitney test for the EORTC QLQ-C30 financial sub-scale are reported below in table 3.9. There was no significant difference between the stoma and non-stoma groups in reported degree of financial difficulties caused by their physical condition or medical treatment, $Z=1.800$; $p>0.05$.

Weight loss

No significant difference was identified between stoma and non-stoma patients on the weight loss sub-scale of the EORTC QLQ-CR38, $Z=1.523$; $p>0.05$. Results of a Mann-Whitney test are reported below in table 3.9.

Table 3.9: EORTC QLQ-C30 and CR38 single item symptom scales results of Mann-Whitney tests.

Scale	Type of surgery [1]	Mean rank	Sum of ranks	Z	Sig.(2-tailed) Sig (*p<0.05)
Dyspnoea	SC (n=21)	16.31	342.50	0.212	0.832 n.s
	SS (n=11)	16.86	185.50		
Insomnia	SC (n=21)	14.95	314.00	1.702	0.089 n.s
	SS (n=11)	19.45	214.00		
Appetite loss	SC (n=21)	16.26	341.50	0.473	0.636 n.s
	SS (n=11)	16.95	186.50		
Constipation	SC (n=21)	17.05	358.00	0.725	0.468 n.s
	SS (n=11)	15.45	170.00		
Diarrhoea	SC (n=21)	17.69	371.50	1.221	0.222 n.s
	SS (n=11)	14.23	156.50		
Financial difficulties	SC (n=21)	15.26	320.50	1.800	0.072 n.s
	SS (n=11)	18.86	207.50		
Weight loss	SC (n=21)	17.55	368.50	1.523	0.128 n.s
	SS (n=11)	14.50	159.50		

[1] SC=sphincter conserving SS=sphincter sacrificing

Problems with defaecation

The problems with defecation sub-scale of the EORTC QLQ CR38 consists of seven items relating to difficulties with bowel movements such as difficulty in moving the bowels, unintentional release of stools and painful bowel movements. This was only completed by patients without a stoma. The 95% confidence interval for the mean is presented below in table 3.10.

Table 3.10: Descriptive statistics for the EORTC QLQ-CR38 problems with defecation sub-scale.

Type of surgery [1]	Mean score	S.D.	Minimum Maximum Range	95% confidence level for mean	
SC (n=22)	14.09	20.54	0.00 99.00 99.00	Lower bound 4.98	Upper bound 23.19

[1] SC=sphincter conserving

Stoma related problems

The stoma related problems sub-scale of the EORTC QLQ-CR38 consists of seven items relating to difficulties with a colostomy bag such as fear that other people would hear the stoma or smell their stools, fear of possible leakage from the stoma and difficulty caring for the stoma. This sub-scale was only completed by patients with a stoma. The 95% confidence interval for the mean is presented below in table 3.27.

Table 3.11: Descriptive statistics for the EORTC QLQ-CR38 stoma related problems sub-scale.

Type of surgery [1]	Mean score	S.D.	Minimum Maximum Range	95% confidence level for mean	
SS (n=11)	15.55	5.66	0.00 99.00 99.00	Lower bound 11.74	Upper bound 19.35

[1] SS=sphincter sacrificing

Statistical Association between measures

Pearson correlation (r) coefficient was used to investigate the strength of the assumed linear association between the measures used in this study. Prior to analysis the relationship between the measurement variables was inspected using a scatterplot diagram.

Emotional functioning

The results of Pearson correlation for the HADS and the EORTC QLQ-C30 emotional functioning sub-scale indicate that there was a significant association between the HADS anxiety sub-scale and the EORTC QLQ-C30 emotional functioning sub-scale, $r=0.779$; $n=32$; $p<0.01$. A significant correlation was also obtained for the Pearson correlation of the HADS depression sub-scale and the EORTC QLQ-C30 emotional functioning sub-scale, $r=0.621$; $n=32$; $p<0.01$.

Body image

The results of Pearson correlation for the two body image measures used in this study indicate that there was a significant association between the BIS and the EORTC QLQ-CR38 body image sub-scale, $r=0.78$; $n=32$; $p<0.01$.

4. Discussion

4.1 Summary of main findings

The results of this study contradict some of the findings of previous research which has explored the quality of life of colorectal cancer patients following sphincter-conserving versus sphincter-sacrificing surgery (e.g. O'Leary et al., 2001; Sprangers et al., 1999; Williams & Johnston, 1983). In this study no statistically significant differences were identified between the two groups across several domains of quality of life including global health status, quality of life, future perspective, physical, psychological, social and sexual functioning and post-surgical symptoms. It is important to consider that differences between the two groups may have existed but were not detected due to insufficient power of this study. Significant differences were found between the two groups in terms of body image satisfaction and male sexual problems. The findings most relevant to this study are discussed below and are compared with those previously reported in the literature.

4.2 Influence of patient and treatment characteristics

A number of studies have been criticised for failing to control for a variety of patient, disease and treatment related variables which some researchers have stated are likely to impact on the results found (White & Hunt, 1997). In the present study statistical analysis revealed that patients were equally distributed across the two groups in terms of age. Length of post-operative period of recovery was found to be significantly shorter in the sample of stoma patients, however, further analysis revealed that this did not have any effect across other variables with the exception of sexual functioning.

Researchers have suggested that the level of psychological adjustment of a patient's partner or significant other has an effect on the patient's own adjustment (Baider, Perez, & Kaplan De Nour, 1989). Although marital status was recorded at interview this information was not included in the main statistical analysis. This may have provided insightful information about possible associations between marital status and level of post-surgical adjustment. There was a notable difference between the two patient groups in terms of marital status with 76% of non-stoma patients compared to only 45% of non-stoma patients who were married. Given the proposed link between the adjustment a patient's partner and their own adjustment this has important implications. Another difference between the two patients groups was the higher number of widows/widowers among the stoma group compared to the non-stoma group, this being 19% and 55% respectively. The marital status of patients may also influence their quality of life due to factors such as practical and emotional support, intimacy and living arrangements.

It has also been suggested that patients with cancer detected by a screening programme may experience less psychological distress, since these cancers may usually be detected earlier and a model of early disease and favourable outcome may be presented (Farmer, Payne, & Royle, 1995). Eleven patients in this sample were detected as part of a screening programme. Due to the small numbers of patients detected by a screening programme across the two groups no further analysis was pursued although this would be a worthwhile investigation in future research. In a study of faecal occult blood testing in colorectal cancer patients Whynes, Neilson, Robinson & Hardcastle (1994) conclude that screening does not seem to have an impact on patients' quality of life even when this involves a positive diagnosis.

Again due to low numbers it was not deemed appropriate to investigate further the possible difference in quality of life between people who underwent emergency surgery and those who did not.

4.3 Discussion of main findings

Global health status quality of life

Although a vast body of research literature reports that colorectal cancer patients who undergo sphincter-sacrificing surgery resulting in a stoma have a worse quality of life than those without a stoma (Camilleri-Brennan & Steele, 1998; Devlin, Plant & Griffin, 1971; Sprangers, Taal, Aaronson & te Velde, 1995; Williams & Johnston, 1983), no difference between stoma and non-stoma patients in terms of overall quality of life was found in this study. The majority of patients consistently rated both their overall health and quality of life highly. Recent studies which compared quality of life in colorectal cancer patients undergoing sphincter-sacrificing and sphincter-conserving surgery also reported no significant difference between the two groups (Allal et al., 1999; Allal et al 2000; Grumann et al., 2001). One explanation for this finding is that more recent research studies may reflect the impact of improved surgical techniques and patient care which is reported to have occurred in recent years (Fielding & Padmanabhan, 1994). It is however necessary to consider overall quality of life in the context of other quality of life domains which are also likely to impact on this rating.

Physical functioning

The fact that there was no difference between stoma and non-stoma patients in relation to physical functioning is perhaps not surprising given the high rating of health status of the

sample. Patients who have undergone curative surgery with no subsequent disease recurrence would not be expected to be significantly physically incapacitated as a result of their disease or treatment at twelve to eighteen months post surgery. This finding is consistent with a study by Allal et al (2000) which reported no significant difference between stoma and non-stoma patients at a minimal interval of one year. Other studies which have reported a difference between the groups have tended to include patients with a wide range of disease stages and at different follow up periods (Allal et al 1999). The findings of a prospective study by Grumann et al (2001) indicated that levels of physical functioning improved between 6 to 9 months and 12 to 15 months post surgery, although no significant difference between stoma and non-stoma patients was found. Therefore, if patients had been interviewed sooner after surgery a lower level of physical functioning would be expected as patients recover from the aftermath of surgery and subsequent treatment. As might be expected Allal et al (1999) found that although there were no significant differences between the two groups in terms of physical functioning, older patients tended to report lower scores indicating poorer physical functioning. This emphasises the need to consider the possible effect of age in reporting on this sub-scale.

Role functioning

The role functioning sub-scale may be regarded as a more appropriate index of quality of life than the physical functioning sub-scale for patients who are at least one year post surgery. Role functioning encompasses the extent to which patients are limited in doing work, daily activities and leisure time activities. It is important to consider the effect of age on level of activity, bearing in mind the generally older adult age group of colorectal cancer patients (Fielding & Padamanabhan, 1994). Gerontologists suggest that as part of the natural ageing process some older adults may gradually become less active and have fewer roles as

a result of their life stage (Ferrell & Ferrell, 1998) irrespective of their disease. It is however important to avoid making generalisations as many older adults often have important and demanding roles such as that of carer to a partner. Consistent with the current study other researchers have found no significant difference between sphincter-conserving and sphincter-sacrificing patients in terms of role functioning (Allal et al, 1999; Allal et al , 2000; Grumann et al, 2001).

Social functioning

A vast amount of research literature has reported that stoma patients often experience reduced social functioning as a result of embarrassment, stigma and worry on relation to their stoma (Devlin et al (1974). In a more recent study by Williams & Johnston (1983) deterioration in social functioning was reported to be more prevalent in stoma rather than non-stoma patients. Similar results have been reported elsewhere (McDonald & Anderson, 1985; Wirsching, Druner & Herman, 1975). In the present study no difference was found between the two groups in terms of their reported level of social functioning. The impact of a person's pre-morbid social functioning in relation to this quality of life domain is essential. Other studies which report differences between stoma and non-stoma patients have tended to use a range of different indicators of social function such as employment, frequency of social contacts and quality of relationships (Sprangers et al., 1995). The variance in operational definition of social functioning used across studies may yield different results (Sprangers et al., 1995). Three recent studies which used the EORTC measures employed in the present study also reported no significant difference between stoma and non-stoma patients in terms of social functioning (Allall et al., 1999; Allal et al 2000; Grumann et al., 2001). It is however important to bare in mind that the current

Psychological functioning

In this study, no statistically significant difference was found between patients who had undergone either sphincter-conserving or sphincter-sacrificing surgery in relation to psychological functioning. This contradicts the findings of previous studies which report that patients with a stoma are more anxious and depressed than patients who do not have a stoma (MacDonald & Anderson, 1984; Williams & Johnston, 1983; Wirsching, Druner & Hermann, 1975). However, several studies in this area have been criticised for not taking into account pre-morbid psychological functioning (White & Hunt, 1997). Effort was taken in this study to ask patients about their previous psychiatric history, if this was felt to be appropriate, as well as relevant information being noted from medical notes. The exclusion criteria for this study stipulated that anyone with a severe psychiatric history existing prior to their cancer treatment would be excluded which was the case with two individuals in the current study. Adherence to the strict inclusion criteria may have contributed to less psychological difficulties being detected in this sample. On the other hand, the researcher was aware of one patient who despite meeting all the requirements of the study inclusion criteria was not included due to concern by the individual's General Practitioner that the patient would become unduly distressed by the interview as the individual had experienced considerable anxiety and depression since her operation. This highlights the possibility that those individuals who volunteer to take part in such research may be more likely to be those who are coping reasonably well rather than those who are finding difficulty adjusting. Without knowing patients' reasons for declining to participate in the present study no firm conclusions can be drawn on this issue. It is important to note that while no statistically significant difference was found in the current study, some individuals (n=4) did achieve clinically significant scores for reported level of anxiety. Other studies have also reported no significant difference between stoma and non-stoma groups in terms of emotional

functioning (Allal et al., 1999; Allal et al., 2000; Grumann et al., 2001). Grumann et al (2001) did find a significant increase in both groups indicating improved emotional functioning over time. Research suggests that the post-operative period is less emotionally distressing when adequate pre-operative preparation has been given (Barsevick, Pasacreta & Orsi, 1995; Kelly & Henry, 1992). In the hospitals in which the current study was performed, patients who were considered highly likely to receive a stoma were given considerable input from stoma nurses both prior to and following their operation. It is important to consider the impact of this support in relation to the current findings.

Future perspective

In this study there was no difference between the two groups in terms of their score for future perspective suggesting that neither group experienced a considerable level of worry about their health in the future. In a study by Allal et al (2000) patients in the sphincter-sacrificing group tended to report higher scores for future perspective, although not statistically significant, compared to sphincter-conserving patients. This may reflect the possibility that patients who undergo more radical surgery are more likely to believe that all the potential area of recurrence has been removed leading to a greater sense of reassurance about the future (Allal et al., 2000). Similar findings and conclusions have been reported in the breast cancer research literature investigating the psychological impact of breast-conserving surgery and mastectomy (Fallowfield & Clark, 1991). This would suggest, as previously highlighted by Kincey & Saltmore (1988) that it is important to consider the potential negative and positive consequences of a particular type of surgery.

Body image

In this study, patients who underwent sphincter-sacrificing surgery resulting in a stoma rated more dissatisfaction with their body image compared to non-stoma patients. This is consistent with the findings of several research studies (e.g. Keltikangas-Jarvinen, Loven & Moller, 1984; Kirkpatrick, 1980; MacDonald & Anderson, 1984; MacDonald & Anderson, 1985; Williams & Johnston, 1983). One of the largest studies in this area was that carried out by Anderson (1982) who from a population of 420 colorectal cancer patients treated with either sphincter- conserving or sphincter-sacrificing surgery reported that colostomy patients rated themselves as having significantly more body image dissatisfaction which was reported to be related to a number of colostomy related cognitions. Length of time elapsed since surgery at which body image is assessed has been suggested to be an important factor (Moyer & Salovey, 1997), as it is assumed that body image issues may become more important to patients at the end of treatment, since during treatment more immediate concerns associated with diagnosis of life threatening illness and managing the effects of treatment may be a priority. In this study, length of period since surgery was found to have no significant effect on body image satisfaction. Other studies (e.g. Goldberg et al., 1992; Lee et al., 1992) in which baseline measures of body image satisfaction were completed using much larger samples have failed to find any association with post-operative length of time. Fallowfield et al (1990) have suggested that patients who are given a choice of treatment appear to do better psychologically irrespective of the type of treatment chosen. However choice of treatment is obviously not possible for all patients although one patient in this study chose to keep the stoma when the possibility of a reversal operation was offered. Other patients in this study expressed strong concerns about having a colostomy to the extent that they stated that this was their first priority immediately post-operation and expressed feeling an overwhelming sense of relief when they realised that they did not have

a colostomy. It is important to consider the potential effect of patients being prepared for the possibility of having a colostomy on subsequent body image satisfaction.

Evidence has shown that side-effects of radiotherapy and chemotherapy can impact on body image (Loesher, Welch-Mccaffrey, Leigh, Hoffman, & Meyskens, 1989). Investigation into the possible effect of radiotherapy and chemotherapy in ratings of body image satisfaction would have been a useful inclusion in the current study.

There have been conflicting results in terms of the relationship between body image and age or marital status (Hopwood, 1992). Again drawing from the vast body of research into breast cancer Penman, Bloom, & Fotopoulis (1987) in a study of women treated for breast cancer with mastectomy found no relationship between age and disfigurement. In contrast to this Metzger, Rogers, & Bauman (1983) found younger women (under 50) to be more likely to be concerned about body image than older women, with unmarried women at greatest risk. This relationship was found to be reversed in the over 60s age group with married women reporting a higher level of concern about their appearance. Research evidence of the association between body image and age and marital status specific to colorectal cancer is scarce.

Sexual functioning

Several researchers have reported the higher prevalence of impaired sexual functioning in individuals with a stoma (e.g. Mannaerts et al 2001; Sprangers et al, 1995; Williams, 1984). In the current study there were no differences between the stoma and non-stoma patients in terms of their rating of sexual functioning and sexual enjoyment. In terms of sexual problems, male stoma patients (n=7) reported significantly more sexual problems than their

male counterparts with no stoma (n=12). The number of females completing the sexual problems sub-scale (n=4) was too low to apply formal statistical analysis. The reasons for low numbers on these sub-scales were two fold. Firstly, there were a number of patients who declined to respond to these questions. This was the case with two postal questionnaires which were returned. Secondly, there were a number of patients who were not sexually active during the four weeks prior to the interview as stipulated in the EORTC QLQ CR38 and therefore the optional part of the questionnaire was left intentionally incomplete. In retrospect it would have been advisable to use a coding system which allowed missing data to be easily differentiated in terms of data missing at random and data missing due to intentional omission. The value of using such procedures for coding data have been recommended elsewhere (Fayers, Aaronson, Bjordal, Groenvold, Curran, & Bottomley, 2001). The results of the current study appear to support previous findings of increased sexual problems in stoma patients although caution should be exercised drawing firm conclusions on the basis of such small sample sizes. In recent studies which have used the EORTC QLQ-CR38 measure of sexual functioning similar results have been reported (Allal et al 1999; Allal et al, 2000; Grumann et al, 2001).

In terms of the number of patients who did not respond to questions, are far as possible effort was taken to sensitively elicit from the patient their current sexual activity status. In some cases it was judged to be inappropriate to pursue this line of enquiry particularly if patients were widowed. This perhaps highlights the importance of taking into consideration a person's relationship status as well as age when interpreting any results regarding sexual functioning in the context of relationship status. Hopwood (1992) however emphasises the importance of avoiding making assumptions on the basis of age or marital status when assessing either body image or sexual functioning. Problems of compliance have been

reported in previous studies, especially when questions have referred to sexual aspects of quality of life (Klee et al., 1997).

A careful and appropriately researched explanation was given during interviews as to the reasons for sexual functioning being enquired about. The fact that potential problems were discussed with some patients in advance of their operation is likely to have important impact in regard to this matter. Although the question of whether any information had been supplied to patients regarding potential impact of treatment on sexual functioning was often discussed during the interview no consistent recording was made of this which prevents further interpretation being made.

Symptomatology

Previous research has documented that many patients suffer from symptoms relating to bowel functioning after surgical treatment such as diarrhoea (Frigell, Ottander, Stenbeck et al., 1990; Karanjia, Schache & Heald, 1992; Lewis et al., 1992; Williams & Johnston, 1983). The research literature suggests that stoma patients tend to report more problems with gas and urinary function while non-stoma patients report more constipation (Baslev & Harling, 1983; Fegiz, Trenti & Bezzi, 1986; MacDonald & Anderson, 1984; Williams & Johnston, 1983). In a study by Grumann et al (2001), patients with a permanent colostomy tended to report less fatigue, gastrointestinal symptoms, sleeplessness, constipation and diarrhoea than patients who underwent sphincter-conserving surgery.

In contradiction to these findings, no differences were found between the groups on sub-scales relating to any of these symptoms. One explanation for this finding is the suggestion in the research literature that bowel function often improves within the first year post

surgery (Frigell, Ottander, & Stenbeck, 1990). The time interval used in this study of at least one year post surgery may mean that for many patients elevation from such symptoms had already occurred by the time they were interviewed. An alternative suggestion is that this may reflect improvements which have been made in recent years in the surgical techniques used, improved colostomy equipment and improvements in patient care. Without a baseline recording of post- operative symptoms it is difficult to say which explanation may be the case in this study. The EORTC QLQ-C38 included one sub-scale which was only completed by patients with a stoma and one sub-scale which was only completed by patients without a stoma these were the defecation sub-scale and the stoma related problems sub-scale respectively. As these scales were not completed by both groups it was not possible to compare their mean scores using independent samples t-tests. The use of descriptive statistics showed that mean scores obtained on these sub-scales were indicative of low levels of symptomatology.

No differences were identified between stoma and non-stoma groups across a range of sub-scales relating to disease symptoms and treatment side-effects. The patients included in the study were selected as having had curative treatment and were not known to have experienced recurrent disease or to have undergone any further treatment during the months preceding the interview. Therefore no significant differences on many of the sub-scales, such as the chemotherapy side-effects sub-scale, were expected in this sample and were therefore not included.

Caution was taken to emphasise to participants that if they felt they were responding to questions for reasons other than those relating to their treatment that this should be made known to the researcher. Given the time constraint of a one hour interview it was not always possible to go through individuals' responses to questionnaires to check the reasons for a

particular response. It was also felt that this may be construed as being rather intrusive when the format of the questionnaires was self-report. One of the difficulties face by the researcher was reminding patients that the assessments used were intended as measures of present functioning as stated on the questionnaires. At times patients tended to think back to their previous illness and treatment. Care was taken to discuss this with the patient if this was felt to be a problem. This does however raise an important issue which could potentially affect results if not clarified by the researcher.

Financial difficulties

Although several patients did report some a minimal degree (n=4) of financial difficulties caused by their medical condition or treatment, no statistically significant differences were found between the stoma and non-stoma patients. Of the four patients who rated some difficulties three had a stoma and all were aged sixty or below with one individual aged thirty five. It is important to emphasise that although no significant difference was found between the two groups in terms of age, the majority of patients in the sample (n=21, 66%) were retired and therefore a major cause of financial difficulties in this population due to the effect of illness on employment did not apply. During the interview several patients commented that financial difficulties might well have been a problem to them had their illness occurred earlier, during their working career.

As discussed earlier, due to the low number of patients recruited, the present study may have lacked sufficient power to detect possible differences between the two groups. There are several other explanations which may also account for the lack of differences identified between the stoma and non-stoma patients. The most relevant ones are discussed briefly below.

It is well documented that considerable adjustment and adaptation occurs during the months following surgery for cancer (Hopwood, 1992). Several researchers have reported that level of psychological distress tends to fluctuate at different time scale throughout the treatment process for cancer (e.g. Grumann et al., 2001). This may mean that due to the long term time scale of this study patients may have adjusted to their altered quality of life and therefore no longer view symptoms or changes associated with their treatment as abnormal or problematic.

Festinger's theory of cognitive dissonance (Festinger, 1957) may be applied to the findings of this study. This theory is based on the assumption that inconsistent cognitions lead to an emotional state of dissonance and uneasiness in a person. Festinger (1957) suggests that generally peoples' response is to reduce dissonance which is achieved by increasing consistency among the dissonant cognitions which usually involves altering attitude relevant cognitions (Fiske & Taylor, 1991). In the case of colorectal cancer patients undergoing surgery resulting in a stoma, one would assume that they do not like the thought of undergoing mutilating surgery but at the same time recognise the need to do so for their survival. Festinger's theory would suggest that these are contradictory cognitions which cause cognitive dissonance to arise and consequent unease in patients. In order to reduce this dissonance patients may have re-evaluated their life with a stoma as overly positive (Bernhard & Hurny, 1998).

It is also relevant to consider the effect of pre-operative expectations on subsequent adjustment. Preconceived ideas about negative impact of a stoma are likely to cause the patient considerable distress and worry about their future. These unduly negative expectations may result in the patient feeling relieved when they realise that their stoma has not restricted them as much as anticipated. This may result in them genuinely regarding their

quality of life as being better than expected (Wan, Counte & Cella, 1997). On a similar theme, patients who are warned of the possibility of a stoma even if this is unlikely which, as discussed earlier, is often the procedure adopted, may feel an overwhelming sense of relief which may compensate for other negative outcomes. This interpretation appeared to fit with the descriptions offered by some patients of their post-operative reaction. It is perhaps however, questionable as to whether this elation would endure in the longer term. Other authors have documented the possibility that patients undergoing less radical forms of surgery may have higher expectations of their post-operative quality of life and may then feel very disillusioned by any treatment side-effects such as bowel and continence problems (Wan, Counte & Cella, 1997). This may account for the findings of some studies which report better long term quality of life in patients undergoing sphincter-sacrificing surgery compared to less radical surgery (Allal et al 2000; Grumann et al., 2001).

Jacobsen, Roth & Holland (1998) describe the powerful emotional bond which patients may develop towards their surgeon. They suggest that the stressful situation of surgery is often accompanied by strong emotions due to the fact that the patient is entrusting their life to the surgeon. This may result in strong feelings of affection and admiration towards the surgeon. Small (1976) likens these emotional reactions to those associated with authority figures in the patient's past. Notably the majority of patients in this study expressed admiration for their surgeon and one might wonder if these feelings of gratitude and sense of loyalty to the surgeon and other staff involved in their care may make it less likely that the patient would report any dissatisfaction with the outcome of their surgery. This theory would benefit from further research and clarification which was beyond the remit of the current study.

Grumann et al (2001) reported on reflection of their research findings that the sample of patients used in their study with a range of different tumour stages and no evidence of

tumour recurrence during a study period of 15 months may represent a sample of patients strongly determined to overcome their cancer. Many researchers, having explored the "fighting spirit" concept, have suggested that patients with a fighting attitude may survive longer than patients who stoically accept their outcome (Cella & Tulsky, 1990; Fawzi, Fawzi & Hyn, 1993; Greer, Morris & Pettingale, 1979; Pettingale, Morris & Greer, 1985; Temoshok, 1987).

4.4 Identified areas for further research

Some researchers have suggested that there may be a difference in certain aspects of quality of life in patients who have undergone a low anterior resection compared to those who were given a high anterior resection. Unfortunately, the routine recording of the distance from the carcinoma to the anal verge was not undertaken in this study and therefore whether the resection was high or low was not consistently recorded. The recording of this data would be an important addition to future research.

Bernhard & Hurny (1998) suggest that for patients with a stoma there is a range of possible psychological outcomes. A positive response may also occur when the colostomy is performed in an attempt to cure cancer in someone previously in good health. At the other end of the spectrum there are patients who are cured of cancer and physically healthy but who become disabled for psychological reasons. Individuals with predisposing conditions such as ulcerative colitis who are diagnosed with colorectal cancer may have more emotional difficulties than those without a medical history due to the added emotional effects of a long-standing chronic illness, often since childhood. There were no patients in the current study known to have a relevant predisposing disease.

4.5 Methodological limitations of the present study

Sample

Sample size

One of the principal limitations of the present study was the relatively small sample size (n=32). Despite the access to a potentially large number of suitable patients this sample size was much smaller than anticipated. Fewer participants than expected were recruited into the study for a variety of different reasons. One of the main reasons for low recruitment was the large number of patients who were deceased by the time patient recruitment for the study began. Many others were classified as 'palliative' due to the recurrence or spreading of their cancer. For some individuals, participation in the study was inappropriate due to their deteriorating general health, which was unrelated to their cancer. For example, five patients were excluded due to progressive neurological illness or due to deterioration in health due to the normal ageing process. Given that the majority of colorectal cancer patients are older adults (Bouchier, 1973) it was anticipated that health problems would be an issue in patient recruitment. Patients were also excluded if they were known to have long-term, severe, mental health problems. The decision to exclude such patients was made on the basis that they may have a high level of psychological distress attributable to their mental health problem rather than to their experience of cancer. A number of patients did not want to participate for unknown reasons. In order to respect patients' wishes and to adhere to the approved research protocol patients were not asked to state a reason for their decision although, some patients volunteered their thoughts. Some patients stated that they did not want to take part in the research as they felt that talking about their experiences would bring back distressing memories. The limited amount of time available in which to complete the study prevented more patients from being contacted. Despite the small sample, evidence of

some statistically significant differences between the two groups in quality of life assessment was demonstrated. These findings are consistent with other studies which employed much larger sample sizes (e.g. Grumann et al., 2001; Williams & Johnston, 1983).

Representativeness of sample

The sample used in this study consisted of a sub-sample of all patients living in Fife who had been surgically treated for colorectal cancer at one of three hospitals during the previous twelve to eighteen months. All patients who met the inclusion criteria were asked to take part. The sample consisted of more women than men, a fact which was to a large extent dictated by the availability and willingness of patients to participate in the study, and was not necessarily representative of the wider group of patients. As mentioned previously, the research literature does suggest that there is a higher ratio of males to females (Fraser & Adelstein, 1982). The mean age of patients in this sample was 66 years of age which is consistent the average age range reported for incidence of colorectal cancer (Bouchier, 1973). Statistical analysis showed that there was an equal distribution of different disease stages and treatment modalities across the two groups.

One of the problems in any investigation of quality of life in cancer patients is the inherent sampling bias, in that only patients who have survived their treatment and who are well enough to be interviewed are included in such studies. This may result in conclusions being made on the basis of an unrepresentative sample. This emphasises the need to acknowledge the extent and presumed effect of missing data which may distort results.

Procedure

Some patients (n=3) requested that the battery of questionnaires be sent to them by post for completion in the privacy of their own home. A major disadvantage of this method was that no clarification of responses to questionnaires could be made by the researcher and no additional information was obtained due to not being able to discuss wider issues relevant to that individual. In retrospect, asking patients for their permission to contact them by telephone after receiving their postal reply might have allowed for valuable discussion and clarification of their responses. Whether or not this would have been acceptable to these patients given their reluctance to participate in a face to face interview is not known. The procedure prior to contacting potential participants for this study was a lengthy process and involved a considerable amount of time and administrative work. It may have been possible to have included more participants had this been a less time-consuming process. With hindsight it would have been preferable if patients had been initially approached by their medical consultant during a routine appointment and informed of this study rather than unexpectedly receiving correspondence from an unknown person. The practical implications of relying on busy medical professionals might however have rendered this unfeasible. Several patients reported initially feeling rather apprehensive when they received correspondence from the clinical psychology department which is based at a hospital well-known locally as a psychiatric hospital and has a degree of stigma associated with it. The patient information sheet provided appeared to provide adequate reassurance. Recruitment to this study might also have been increased if patients could have been seen when they were attending a routine check up appointment at the hospital. This would have prevented the need for patients to travel to the hospital especially for the research interview or having to been visited at home. However, one could argue that patients may prefer to be interviewed in a more neutral setting unconnected to their previous illness and treatment.

Design

Prior to commencing the current study, the researcher's original intention was to carry out a prospective design. However on discussing the practicality of this with a medical consultant it was judged that this would be over-ambitious within the given time scale. This was mainly due to the fact that colorectal cancer patients often have to wait some weeks following diagnosis before surgery is carried out. In addition, due to the extensive nature of the surgery involved, patients would require several weeks if not months to recover before any meaningful quality of life assessment could be made.

There are a number of limitations of the retrospective design used in this study. This type of design does not provide a baseline measure from which to compare results of later assessment. This made it difficult to accurately assess the extent to which psychological distress and impairment to quality of life had resulted from patients' cancer treatment rather than from other extraneous factors such as another illness or life event. During the research interviews effort was made to explore patients' responses to questionnaires in relation to other possible influences. For example, if a patient was known to have a major physical health complaint such as a history of heart disease they were asked to what extent this may have affected their quality of life in isolation from their cancer treatment. Through careful discussion with relevant colleagues it was felt that the most appropriate approach in such circumstances was to decide on an individual basis the appropriateness of inclusion in the study based on carefully weighing up the impact of the relevant factors on quality of life. The advantage of a prospective study design which involves repeated measures at different intervals such as that of Grumann et al (2001) is that confounding variables may be more easily monitored and controlled for. Despite certain weaknesses that are inherent in the retrospective design of the present study, significant results were found.

Due to the low numbers of patients recruited, as discussed earlier, patients who had undergone different treatment modalities were included in the study. In order to accurately measure differences across patients in terms of the impact of surgery on quality of life, controlling for the possible confounding effect of adjuvant therapy on quality of life would have been an advantage. Indeed, the potentially negative psychological impact of such treatment has been well documented (e.g. Greenberg, 1998; Knobf, Pasacreta, Valentine & McCorkle, 1998).

4.6 Critique of measures used

Hospital anxiety and depression scale (HADS)

Several researchers have recommended the HADS (Zigmond & Snaith, 1983), because it is short and does not contain any somatic items (Aaronson et al., 1988; Maguire & Selby, 1989; Selby, 1992). It has been successfully used with cancer patients (Archard & Zittoun, 1993; Cody et al., 1993), and has been reported to be acceptable to patients (Clark & Fallowfield, 1986).

European Organisation for Research Cancer Trials (EORTC QLQ-C30)

European Organisation for Research Cancer Trials (EORTC QLQ-CR38)

The scales of the EORTC developed by Aaronson et al (1998, 1991, 1993) are reported to be the most extensively used, tested and highly recommended by national and international bodies (Osoba, 1991). The main advantage of using these scales was their good reliability and validity for their use with cancer patients. While several authors have highly recommended the use of the EORTC QLQ measures they have been criticised for being lengthy (Saunders & Baum, 1992). Although initially patients appeared to be put off by the

presentation of questionnaires several pages long they were able to complete the measures fairly rapidly and with relative ease. The number of sub-scales included in the EORTC measures was rather overwhelming in terms of statistically analysing and interpreting the data. One solution to this problem would have been to have selected only the sub-scales of particular relevance to this study prior to data analysis. The danger in doing so is that this would have compromised the established reliability and validity reported for the measures which stipulates that both complete measures must be used in research studies. The alternative approach would have been to select relevant scales retrospectively following analysis, however this could be construed as manipulated the results as the selection made by the researcher may have been biased. An additional difficulty of using lengthy scales with several subs-scales is that the number of statistical tests required increases the risk of obtaining statistical significance by chance (Fitzpatrick et al., 1998). Unfortunately the EORTC scales have not been designed to provide a total quality of life score consisting of the summation of individual sub-scale scores. This would have been a useful aid in comparing differences between the two groups of patients in this study. An important advantage of using the EORTC QLQC-R38 was that in using a disease-specific scale it allowed information which is clinically and socially significant to colorectal cancer patients to be obtained (Bowling, 2001).

Body Image Scale (BIS)

The use of the BIS in the present study was appropriate as the scale was intended to be used either in conjunction with the EORTC QLQ-30 or as a specific measure in its own right. The inclusion of this scale in the battery of measures allowed additional items relevant to body image to be explored. The instructions given on the BIS ask the patient to complete the questions with reference to the past week which is in keeping with the time frame used in

the EORTC QLQ-C30 (Thompson, 1992). The main advantages of the BIS are its brevity and its reported psychometric robustness (Hopwood, Fletcher, Lee & Ghazal, 2001). It has been reported to be applicable to different groups of cancer patients including colorectal cancer patients and has been found to be acceptable to both male and female patients with a range of different body image concerns (Hopwood, Fletcher, Lee & Ghazal, 2001). To date no appropriate cut-off score for body image disturbance has been established, which in the current study would have provided valuable clinical information in identifying patients who may benefit from psychological intervention. However, its main purpose is to allow for comparisons to be made between groups. As Hopwood et al (2001) point out the task of establishing an appropriate cut-off score for body image disturbance is complicated by the fact that there is no agreed diagnostic criteria for body image disturbance or standardised interview assessments.

Overall, the measures appeared to be acceptable to patients and were practical in terms of the level of complexity of questions included, amount of information obtained and the time required for completion. With the exception of the items relating to sexual functioning a high level of compliance was obtained in this study. From the statistical analysis carried out there appeared to be a relatively high level of correlation between specific measures. This was expected given that items from the BIS and HADS are incorporated into the EORTC measures.

4.7 Conclusion

Compared to other cancers, colorectal cancer has received relatively little attention in terms of research, although in recent years there has been an increasing amount of research in this area, particularly due to the development of the EORTC cancer specific quality of life measurements and evaluation studies of colorectal cancer screening programmes. Due to the complex issues involved in carrying out reliable and valid quality of life evaluation there is a much needed impetus for further research, ideally well-controlled studies using a prospective study design.

The sample of patients in this study showed evidence of differences in body image and sexual functioning both of which are recognised as being important domains of quality of life. Whether the higher levels of body image dissatisfaction and sexual problems in stoma patients are due to treatment side-effects, difficulties in psychological adjustment or both the fact that these difficulties may persist long after initial treatment requires further attention.

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Fife Primary Care NHS Trust

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NHS
Fife

Date 10/11/02

Your Ref
Our Ref CS thesis

Enquiries to
Extension 336 or 217
Email psychology@fife-pct.scot.nhs.uk

Dear

I work within Fife Primary Care NHS Trust and I am currently carrying out research into the quality of life in people who have had colorectal cancer (bowel cancer). It is hoped that by exploring this area we will be better informed of patients' needs and will be able to improve the care offered to colorectal (bowel) cancer patients in the future. Your contribution to this study would be valuable. I have enclosed an information sheet explaining the study in more detail. Please read the information sheet carefully before deciding whether or not you wish to take part in this study. Your participation is entirely voluntary. If you decide that you do not wish to take part this will not in any way affect your future treatment and medical care. Any information provided as part of the study will remain confidential. Your GP and your Consultant are already aware of this research being carried out. The research study has received ethical approval from Fife Health Board ethics committee.

Unless I hear otherwise I will assume that you have no objections to me contacting you within the next few days to invite you to take part in this study.

Should you require any further information please contact me at the above address or telephone number where I will be happy to discuss this with you.

Yours sincerely

Caroline Somerville
Psychologist
Enc.

PATIENT INFORMATION SHEET

RESEARCH STUDY: QUALITY OF LIFE IN COLORECTOR (BOWEL) CANCER PATIENTS

Please read the following information carefully. This leaflet explains what this research is about and why you have been asked to take part.

What is this study about?

This study aims to explore the quality of life of colorectal cancer patients who have had surgical treatment. Other research studies suggest that surgery for colorectal cancer can have major effects on peoples' day to day functioning and their quality of life. It is hoped that the results of this study will help us to better understand the effects of surgery and will help to inform us about ways in which we can improve the treatment offered to colorectal cancer patients in the future.

Who is carrying out the study?

The study is being carried out by Caroline Somerville, Clinical Psychologist in Training, as part of a Doctorate in Clinical Psychology.

Who is being asked to take part in the study?

Patients who have had surgery for colorectal cancer during the last twelve to eighteen months will be asked to take part in this study.

Do I have to take part?

No, taking part in this study is entirely voluntary. If you decide that you do not want to take part this will not affect your treatment and medical care in anyway.

What will be involved if I agree to take part?

If you decide to take part in the study you will be asked to complete a few short questionnaires. This will only take approximately half an hour. This will either be done at an out-patient clinic or at your home depending on which is more convenient for you.

PLEASE TURN TO NEXT PAGE

Will my information be confidential?

Yes. Any information you give will be anonymous and confidential.

What will happen to the results of this research study?

The information collected will be used for writing an academic piece of work and perhaps for publication in a scientific journal. In these instances, no information about your identity will be included. If you are interested in obtaining reports or published articles of research, copies will be supplied by the researcher.

What happens next?

You will be contacted within a couple of weeks of receiving this information sheet to ask you whether or not you wish to take part in this study. If for any reason you do not wish to be contacted please let the researcher know by contacting her at the address or telephone number given below. Your decision will be respected and you will not be contacted again. If you do wish to take part in the study a convenient time will be arranged with you.

If you have any questions or would like any further information please contact:

Caroline Somerville
Clinical Psychologist in Training
Department of Clinical Psychology
Stratheden Hospital
Cupar
Fife
KY15 5RR

Telephone: 01334 652 611 Ext 336

Thank you for taking the time to read this information sheet. Please keep this copy.

EORTC QLQ-C30 (version 3)

We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.

Please fill in your initials: ⌊_____⌋
Your birthdate (Day, Month, Year): ⌊_____⌋
Today's date (Day, Month, Year): 31 ⌊_____⌋

		Not at All	A Little	Quite a Bit	Very Much
1.	Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	1	2	3	4
2.	Do you have any trouble taking a long walk?	1	2	3	4
3.	Do you have any trouble taking a short walk outside of the house?	1	2	3	4
4.	Do you need to stay in bed or a chair during the day?	1	2	3	4
5.	Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4

During the past week:

		Not at All	A Little	Quite a Bit	Very Much
6.	Were you limited in doing either your work or other daily activities?	1	2	3	4
7.	Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
8.	Were you short of breath?	1	2	3	4
9.	Have you had pain?	1	2	3	4
10.	Did you need to rest?	1	2	3	4
11.	Have you had trouble sleeping?	1	2	3	4
12.	Have you felt weak?	1	2	3	4
13.	Have you lacked appetite?	1	2	3	4
14.	Have you felt nauseated?	1	2	3	4
15.	Have you vomited?	1	2	3	4

During the past week:		**Not at All**	**A Little**	**Quite a Bit**	**Very Much**
16.	Have you been constipated?	1	2	3	4
17.	Have you had diarrhea?	1	2	3	4
18.	Were you tired?	1	2	3	4
19.	Did pain interfere with your daily activities?	1	2	3	4
20.	Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	1	2	3	4
21.	Did you feel tense?	1	2	3	4
22.	Did you worry?	1	2	3	4
23.	Did you feel irritable?	1	2	3	4
24.	Did you feel depressed?	1	2	3	4
25.	Have you had difficulty remembering things?	1	2	3	4
26.	Has your physical condition or medical treatment interfered with your family life?	1	2	3	4
27.	Has your physical condition or medical treatment interfered with your social activities?	1	2	3	4
28.	Has your physical condition or medical treatment caused you financial difficulties?	1	2	3	4

For the following questions please circle the number between 1 and 7 that best applies to you

29. How would you rate your overall health during the past week?

1	2	3	4	5	6	7
Very poor						Excellent

30. How would you rate your overall quality of life during the past week?

1	2	3	4	5	6	7
Very poor						Excellent

EORTC QLQ – CR38

Patients sometimes report that they have the following symptoms or problems. Please indicate the extent to which you have experienced these symptoms or problems during the past week. Please answer by circling the number that best applies to you.

During the past week :	**Not at All**	**A Little**	**Quite a Bit**	**Very Much**
31. Did you urinate frequently during the day?	1	2	3	4
32. Did you urinate frequently during the night?	1	2	3	4
33. Did you have pain when you urinated?	1	2	3	4
34. Did you have a bloated feeling in your abdomen?	1	2	3	4
35. Did you have abdominal pain?	1	2	3	4
36. Did you have pain in your buttocks?	1	2	3	4
37. Were you bothered by gas (flatulence)?	1	2	3	4
38. Did you belch?	1	2	3	4
39. Have you lost weight?	1	2	3	4
40. Did you have a dry mouth?	1	2	3	4
41. Have you had thin or lifeless hair as a result of your disease or treatment?	1	2	3	4
42. Did food and drink taste different from usual?	1	2	3	4
43. Have you felt physically less attractive as a result of your disease or treatment?	1	2	3	4
44. Have you been feeling less feminine/masculine as a result of your disease or treatment?	1	2	3	4
45. Have you been dissatisfied with your body?	1	2	3	4
46. Were you worried about your health in the future?	1	2	3	4

During the past <u>four</u> weeks:	**Not at All**	**A Little**	**Quite a Bit**	**Very Much**
47. To what extent were you interested in sex?	1	2	3	4
48. To what extent were you sexually active (with or without intercourse)?	1	2	3	4
49. Answer this question only if you have been sexually active: To what extent was sex enjoyable for you?	1	2	3	4

Please go on to the next page

During the past four weeks:

	Not at All	A Little	Quite a Bit	Very Much
For men only:				
50. Did you have difficulty getting or maintaining an erection?	1	2	3	4
51. Did you have problems with ejaculation (e.g., so-callled "dry ejaculation")?	1	2	3	4
Only for women who have had intercourse:				
52. Did you have a dry vagina during intercourse?	1	2	3	4
53. Did you have pain during intercourse?	1	2	3	4

54. Do you have a stoma (colostomy bag)? **(Please circle No or Yes)**

No — **Please answer questions 55 to 61**

Yes — **Please skip questions 55 to 61 and answer questions 62 to 68**

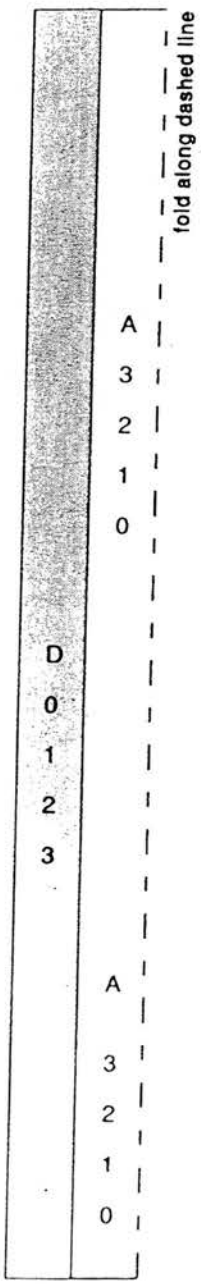
During the past week:

	Not at All	A Little	Quite a Bit	Very Much
Only for patients WITHOUT a stoma (colostomy bag):				
55. Did you have frequent bowel movements during the day?	1	2	3	4
56. Did you have frequent bowel movements during the night?	1	2	3	4
57. Did you feel the urge to move your bowels without actually producing any stools?	1	2	3	4
58. Have you had any unintentional release of stools?	1	2	3	4
59. Have you had blood with your stools?	1	2	3	4
60. Have you had difficulty in moving your bowels?	1	2	3	4
61. Have your bowel movements been painful?	1	2	3	4
Only for patients WITH a stoma (colostomy bag):				
62. Were you afraid that other people would be able to hear your stoma?	1	2	3	4
63. Were you afraid that other people would be able to smell your stools?	1	2	3	4
64. Were you worried about possible leakage from the stoma bag?	1	2	3	4
65. Did you have problems with caring for your stoma?	1	2	3	4
66. Was your skin around the stoma irritated?	1	2	3	4
67. Did you feel embarassed because of your stoma?	1	2	3	4
68. Did you feel less complete because of your stoma?	1	2	3	4

Hospital Anxiety and Depression Scale

NFER-NELSON
Health & Social Care

Name	Date . . . . .



Clinicians are aware that emotions play an important part in most illnesses. If your clinician knows about these feelings she or he will be able to help you more.

This questionnaire is designed to help your clinician to know how you feel. Ignore the numbers printed on the left of the questionnaire. Read each item and **underline** the reply which comes closest to how you have been feeling in the past week.

Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought-out response.

I feel tense or 'wound up':

- Most of the time
- A lot of the time
- From time to time, occasionally
- Not at all

I still enjoy the things I used to enjoy:

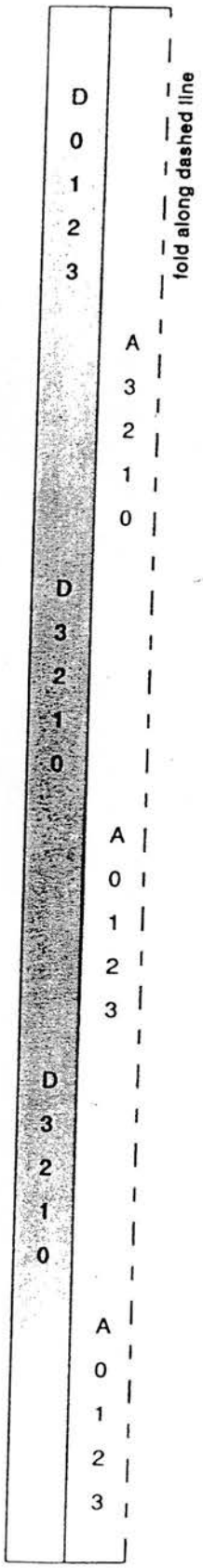
- Definitely as much
- Not quite so much
- Only a little
- Hardly at all

I get a sort of frightened feeling as if something awful is about to happen:

- Very definitely and quite badly
- Yes, but not too badly
- A little, but it doesn't worry me
- Not at all

(continued overleaf)

HOSPITAL ANXIETY AND DEPRESSION SCALE



I can laugh and see the funny side of things:

As much as I always could

Not quite so much now

Definitely not so much now

Not at all

Worrying thoughts go through my mind:

A great deal of the time

A lot of the time

From time to time but not too often

Only occasionally

I feel cheerful:

Not at all

Not often

Sometimes

Most of the time

I can sit at ease and feel relaxed:

Definitely

Usually

Not often

Not at all

I feel as if I am slowed down:

Nearly all the time

Very often

Sometimes

Not at all

I get a sort of frightened feeling like 'butterflies' in the stomach:

Not at all

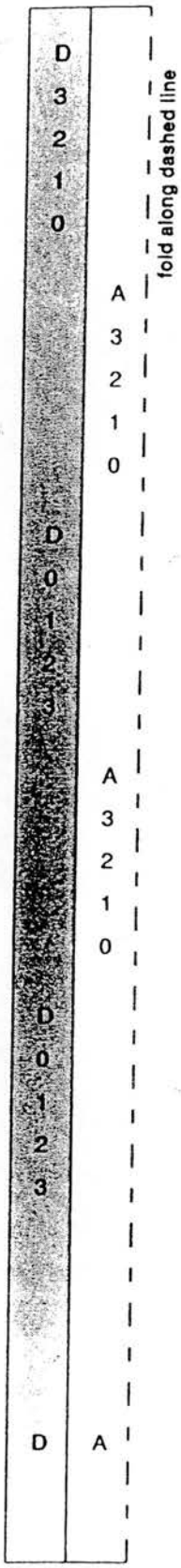
Occasionally

Quite often

Very often

(continued overleaf)

HOSPITAL ANXIETY AND DEPRESSION SCALE



I have lost interest in my appearance:

Definitely

I don't take as much care as I should

I may not take quite as much care

I take just as much care as ever

I feel restless as if I have to be on the move:

Very much indeed

Quite a lot

Not very much

Not at all

I look forward with enjoyment to things:

As much as ever I did

Rather less than I used to

Definitely less than I used to

Hardly at all

I get sudden feelings of panic:

Very often indeed

Quite often

Not very often

Not at all

I can enjoy a good book or radio or TV programme:

Often

Sometimes

Not often

Very seldom

Now check that you have answered all the questions

For office use only:

D : ☐ Borderline 8–10

A : ☐ Borderline 8–10

Body Image Questionnaire

In this questionnaire you will be asked how you feel about your appearance, and about any changes that may have resulted from your disease or treatment. Please read each item carefully, and place a firm tick on the line alongside the reply which comes closest to the way you have been feeling about yourself, during the past week.

	Not at all	A little	Quite a bit	Very much
Have you been feeling self-conscious about your appearance ?	.....	.....	.....	.....
Have you felt <u>less</u> physically attractive as a result of your disease or treatment ?	.....	.....	.....	.....
Have you been <u>dissatisfied</u> with your appearance when dressed ?	.....	.....	.....	.....
Have you been feeling <u>less</u> masculine/feminine as a result of your disease or treatment ?	.....	.....	.....	.....
Did you find it difficult to look at yourself naked ?	.....	.....	.....	.....
Have you been feeling <u>less</u> sexually attractive as a result of your disease or treatment ?	.....	.....	.....	.....
Did you avoid people because of the way you felt about your appearance ?	.....	.....	.....	.....
Have you been feeling the treatment has left your body less whole ?	.....	.....	.....	.....
Have you been <u>dissatisfied</u> with your body ?	.....	.....	.....	.....
Have you been <u>dissatisfied</u> with the appearance of your scar ?	.....	.....	.....	.....
	....N/A			

Dr P Hopwood, CRC Psychological Medicine Group, Stanley House Christie Hospital, Wimslow Road, Withington Manchester.